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Wendy A. Pearse BSc Hons

**A Qualitative study exploring relatives' experience
of seeking help for a person during the early stages
of schizophrenia**

**A thesis submitted in partial fulfilment of the requirements of the Open University
for the degree of Doctor of Clinical Psychology**

JULY 1998

SALOMONS

CANTERBURY CHRIST CHURCH COLLEGE

(approx. 20 000 words)

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ACKNOWLEDGEMENTS

I would firstly like to thank all the relatives who kindly volunteered to take part in this research. For some it was a difficult decision but one that I am grateful that they made. I only hope that I have been able to effectively represent the intensity of their experiences.

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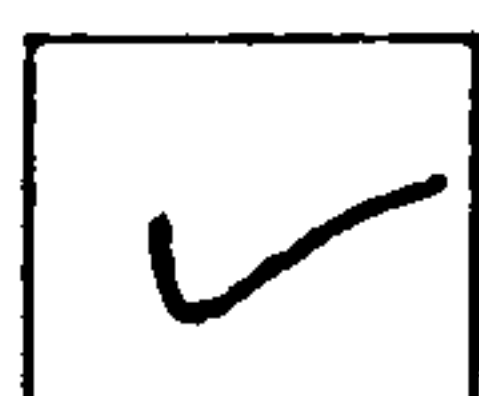
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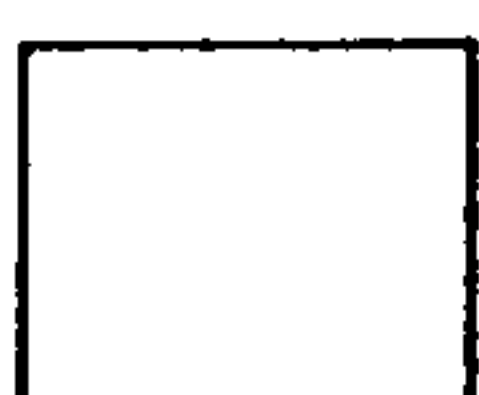
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ABSTRACT

Background

Research suggests that early intervention for schizophrenia improves prognosis and prevents relapse, but factors which influence early access to services still remain unclear. Two factors which have been implicated, however, are family involvement and gender of the person.

Aims

The current study set out to explore relatives' experience of seeking help for a person during the early stages of schizophrenia. This was to be considered in general terms and with particular reference to the influence that the gender of the person had on this process.

Participants

Clients with a diagnosis of schizophrenia in the last fifteen years were identified through routine clinical services and their permission sought to contact a relative. Eight relatives of men, and eight relatives of women, with schizophrenia were recruited.

Methodology

A qualitative methodology was used. Relatives were interviewed about their experience using a semi-structured interview schedule. Results were analysed using a Grounded Theory method (Glaser and Strauss, 1990).

Major Findings

A theoretical framework for understanding the process of relative's adjustment to their experience was developed. The framework suggests that there are four inter-related phases that relatives go through during their help seeking experience. The framework also suggests that resolution is achieved when relatives' needs are adequately met in the following four areas: Understanding; Action; Integration of Difference; and Communication/Interaction. Implications for Clinical Practice, Service Delivery and further research are discussed.

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1. Introduction

1.1 In the Beginning

Several years ago, the researcher was involved in a study to evaluate a programme of support for the families of schizophrenia sufferers (Cogan & Salvidge, 1996). The researcher spent many hours interviewing families, hearing about their difficulties and concerns, and finding out about their impressions of the support they had received. Time and time again the researcher heard the same phrase repeated by the different families:

“If only we’d had this in the beginning”

What? What is it that they wanted in the beginning? From this constantly reiterated phrase, the researcher began to realise that, from the perspective of the relatives, the majority had found the initial stages of schizophrenia the most difficult period to cope with and one where there seemed to be little help available. Why was this so? What was it that relatives were asking for? How could appropriate help be provided? These questions ran through the researcher’s mind.

There were many books and papers written on the needs of relatives in the later stages of schizophrenia, from both an intervention perspective (for example: Lam, 1991; Tarrier, Barrowclough, Porceddu & Fitzpatrick, 1994) and a support perspective (for example: Norbeck, Chafetz, Skodol-Wilson & Weiss, 1991; Shepherd, Murray & Muijen, 1994). However, surprisingly little was documented on the experiences of families in the very early stages of schizophrenia. So what *were* the experiences of relatives? How could these be most appropriately addressed?

It was these questions, therefore, those which had arisen from the above phrase: *“If only we’d had this in the beginning”*, which sowed the seeds of curiosity in the researcher’s mind. These were the seeds from which the current study germinated.

1.2 Overview

Family involvement in schizophrenia has been a topic of interest since the late 1940s when the psychoanalytic literature began to implicate the family in the aetiology of schizophrenia (Fromm-Reichmann, 1948). However, one of the negative aspects of implicating the family in the aetiology of schizophrenia has been to create much guilt on the part of families and blame on the part of professionals, thereby often driving a rift between them. One of the positive aspects, however, is that it did highlight the need for psychosocial interventions and by focusing on the family as a whole, has led to work on how the family influences the course and prognosis of the illness. For example, the work on expressed emotion within the family developed in this way (Vaughn, 1989).

Currently, most interventions for schizophrenia are based upon the 'stress-vulnerability model' (Zubin & Spring, 1977; Nuechterlein & Dawson, 1984) and interventions involving families are mostly aimed at preventing relapse. However, in recent years there has been much interest in the concept of early intervention in schizophrenia. Current interest has now, turned towards interventions focused upon when people show the first signs of schizophrenia, a period sometimes known as 'schizophrenia prodrome' (Birchwood, McGorry & Jackson, 1997). This is because it has been noted that the shorter the duration of untreated psychosis (DUP) a person experiences, then the better their prognosis (Loebel, Lieberman, Alvir, Mayerhoff, Geisler & Szmanski, 1992). It has been also noticed that in many cases there is a considerable lag between the onset of first symptoms and receipt of specialist psychiatric care. The reasons for this treatment lag are unclear although many factors have been implicated.

One such factor implicated, has been the influence of the family, although there is no clear evidence as to how strongly and in what ways the family influences this process (Vaglum, 1996). Suggestions have included: difficulty recognising symptoms of schizophrenia (Jackson & Birchwood, 1996); a slow deterioration in function over time increases the threshold that families have to surmount to seek help (Larsen, McGlashen, Johannessen & Vibe-Hansen, 1996a); help-seeking by families is impeded by negative social attitudes to mental illness (Perkins & Moodley, 1993); and families have difficulty accessing care through GPs (Johnstone, Crow, Johnson & MacMillan, 1986). Another factor implicated in treatment lag is the gender of the person with schizophrenia. It has been found that, on average, women have a significantly lower DUP than men (39 weeks versus 154 weeks) (Larsen, et al., 1996a). However the reasons for this difference are unclear.

So the question remains of how best to investigate the impact of the family on the prodromal phase of schizophrenia and also how the prodromal phase of schizophrenia impacts upon the family. The overall aim of this study, therefore, was to develop a greater insight into the family's perspective of their experience in order to gain some understanding of the family's role in helping a relative to receive appropriate mental health services. In particular the study aimed to illuminate the following: what families thought and felt about their experience; the processes by which families decided that there was something 'different' about the person and to then seek professional help; what the experience of making contact with professional services was like; how issues such as past experience of mental disorder and gender of the person influence families' experience.

A qualitative methodology, Grounded Theory (Strauss & Corbin, 1990), was considered best suited to achieve the aims of the study. The study was a within and between participants design, exploring the experiences of relatives of people with schizophrenia. A comparison was made between the experiences of relatives of women with schizophrenia and the experiences of relatives of men with schizophrenia.

1.3 Schizophrenia

1.3.1 What is Schizophrenia?

According to the World Health Organisation's International Classification of Mental and Behavioural Disorders (ICD-10) schizophrenia is considered to be a mental disorder in which hallucinations, delusions and gross behavioural disturbances are characteristic (WHO, 1992). ICD-10 breaks the diagnosis of schizophrenia into 9 further categories which it refers to as the 'schizophrenic disorders', all characterised, in general, by distortions of thinking and perception, and by inappropriate or blunted affect. In order for a diagnosis of schizophrenia (or a schizophrenic disorder) to be made, the person has to have experienced either one very clear symptom (i.e. delusions or hallucinations) or two or more less clear symptoms (as detailed in ICD-10). These should have been clearly present for a period of one month or more.

The Diagnostic and Statistical Manual for Mental Disorders (DSM IV) (APA, 1994) uses a similar though not identical diagnostic system to the ICD-10. The major difference is that DSM-IV stipulates that the symptoms must have been present for a minimum of six months.

Schizophrenia, as a diagnosed mental disorder, has an incidence of approximately 1 in 1000 population (Wing, 1987) and a prevalence of 1.5 to 5.1 per 1000 internationally (Jablensky & Sartorius, 1975). It is a condition, therefore, that although it has a low incidence, has a much higher prevalence rate because of its chronicity. This, therefore, has implications for long-term care needs.

1.3.2 Schizophrenia as a diagnosis

There has, however, been much criticism and debate about schizophrenia as a diagnosis and suggestions that it is of no diagnostic value as there is no firm evidence that such a syndrome exists (Bentall, 1986). This does not imply that the difficulties people experience do not exist but just emphasises the heterogeneity of such difficulties, arguing that schizophrenia is, primarily, a socially constructed concept (Boyle, 1990).

One of the main arguments against the usefulness of the schizophrenia diagnosis is based upon its reliability and validity. For a diagnosis to be reliable, different clinicians must be able to agree that specific symptoms are present. The DSM-IV and ICD-10 both have internal reliability as diagnostic tools but the reliability between these systems still remains relatively poor (McGuffin, Farmer & Harvey, 1991).

With validity, however, greater difficulties arise. For a diagnosis to be valid it can be assessed in three ways (Bentall, 1993). First, the concept of schizophrenia should map onto a cluster of symptoms that occur together in real life. Secondly, the diagnosis should be able to predict course, outcome and response to treatment. Thirdly, diagnosis should relate to aetiology. As it stands, the current body of evidence cannot support, with any certainty, any of the above criteria and so therefore there is doubt about whether the concept of schizophrenia can be considered as valid (Bentall, Jackson & Pilgrim, 1988).

These difficulties have led to suggestions that the concept of schizophrenia be abandoned (Bentall, et al., 1988) and instead, people's difficulties be addressed on an individual 'symptom'-based approach (Bentall, 1993; Costello, 1993). This method of 'diagnosis' also casts an interesting doubt over whether the classification of psychotic experiences and behaviours should remain as categorical or should be seen as dimensional.

1.3.3 Terminology

Currently, however, despite the above criticisms, the mental health services are still very much driven and/or influenced by psychiatry and the associated ‘medical model’. This means that the majority of the research literature, and the services available to people, are often based within this framework. In most instances, therefore, the relatives, and often the person themselves, commonly understand and refer to schizophrenia within an ‘illness’ framework. It is for this reason that this study uses some medical model terminology by referring to schizophrenia either as a mental disorder or as a mental ‘illness’. The arguments as to the limitations of the terminology will only be addressed where they specifically inform other aspects of the study.

1.4 Current Treatments and Interventions for Schizophrenia

1.4.1 Drug Treatment

Anti-psychotic medication is used almost universally as the main treatment for people diagnosed as having schizophrenia, at least in the ‘acute’ phases of the disorder (Hemsley, 1995). It is estimated that 66.7 percent of people diagnosed with schizophrenia use some sort of anti-psychotic medication (Weyerer & Dilling, 1991).

A number of studies have demonstrated that medication has a beneficial effect for many people with acute schizophrenia (Hemsley, 1995). However, medication is often not effective in treating the ‘negative’ symptoms of schizophrenia (e.g. social withdrawal, blunting of affect) and in approximately 10-30 percent of people, medication may have no beneficial effect at all (Hall, 1997). It is therefore often necessary to use other treatments in combination with, or instead of, drug treatments.

1.4.2 Psychological Approaches

The most widely used psychological approach to the treatment of schizophrenia is the use of cognitive behavioural therapy focused on hallucinations and delusions. This approach does not aim to eliminate psychotic symptoms but emphasises the development of effective coping strategies (Nelson, 1997). Recent well-controlled trials of this type of intervention have been

shown to be highly effective on both psychotic symptoms and speed of recovery (Drury, Birchwood, Cochrane & MacMillan, 1997a; Drury, Birchwood, Cochrane & MacMillan, 1997b).

1.4.3 Family Interventions

Currently, the majority of interventions for schizophrenia are based upon the 'stress-vulnerability' model (Zubin & Spring, 1977; Nuechterlein & Dawson, 1984). This model suggests that some people are inherently vulnerable to the development of schizophrenia (e.g. genetic inheritance; personality factors) and that if the person is subjected to a certain degree of psychological and/or environmental stress then schizophrenia is likely to be precipitated. This model also suggests that these stresses can precipitate relapse.

Interventions involving the family have been mostly aimed at preventing relapse by minimising environmental stress within the family. The now well established link between high EE shown in relatives and the poorer outcome and increased relapse rates in schizophrenia (Vaughn, 1989; Falloon, 1988) has formed the basis for the majority of the psycho-educational programmes used with families. These programmes have been shown to be generally successful. For example, in a well known study by Leff, Kuipers, Berkowitz, Eberlein-Vries & Sturgeon (1982) a package of family interventions was shown to influence relapse rate significantly (i.e. 50 percent relapse rate in control group vs. 9 percent relapse rate in experimental group). In this study, the influence at two-year follow up was not so strong although good results have been found in other studies (e.g. Tarrier, Barrowclough, Vaughn, Bamrah, Porceddu, Watts and Freeman, 1989).

1.5 Improving prognosis through early intervention

It has been shown that early intervention during the initial stages of schizophrenia improves prognosis and postpones further relapse (Birchwood, MacMillan & Smith, 1994). Until recently, most early interventions with schizophrenia have focused upon relapse prevention, particularly in relation to the period after first presentation to psychiatric services.

In the last few years however, much interest has been shown in another critical period which occurs before the initial episode of schizophrenia, known in the literature as 'duration of untreated psychosis' (DUP). In most cases of schizophrenia the onset of frank psychosis is

preceded by a period of prodromal features (McGorry, McFarlane, Patton, Bell, Hibbert, Jackson & Bowes, 1995). This has been encapsulated in the DSM-V category as ‘schizophrenia prodrome’, although clinically these features may, as yet, not be sufficient evidence of early schizophrenia (McGorry et al., 1995).

A lengthy DUP, however, has been related to poorer outcome in schizophrenia, and it is suggested that intervention at an earlier stage is likely to improve outcome (Malla, McLean & Norman, 1997; Drew & Howe, 1997). So, if earlier intervention improves prognosis and if it is possible to detect ‘schizophrenia prodrome’, it is probable that if people seek help quickly this would reduce their DUP and so improve prognosis.

1.6 Treatment Lag

Many people, however, take a long time to gain treatment for their initial episode of schizophrenia (Johannessen, 1997) and several studies have reported a ‘treatment lag’ between onset of symptoms and eventual contact with psychiatric services (Lincoln & McGorry, 1995; Welham, Pemberton, & McGrath, 1996). A recent study found that in 75 percent of cases of schizophrenia, first admission was preceded by a prodromal phase with a mean length of 5 years and psychotic pre-phase of one year’s duration (Hafner & an der Heiden, 1997).

If early intervention is important it seems necessary, therefore, to have knowledge about the factors which strongly influence treatment lag. Initial research suggests it is influenced by several factors including: socio-demographics, type of disorder and accessibility of health services (Vaglum, 1996); individual and family attitude to mental illness and stigma (Perkins & Moodley, 1993); insidious onset of schizophrenia (Rhi, Ha, Kim, Sasaki, Young, Woon, Tai-Hwang, Laraya & Yanchun, 1995); negative symptoms (Larsen, McGlashan & More, 1996b); gender (Larsen, et al, 1996a); and GP’s knowledge of mental illness (Jackson & Birchwood, 1996).

It seems, therefore, that gaining access to secondary mental health services where appropriate treatment can be received is possibly influenced by any number of issues, at any level within the person’s system. However, none of these factors have been studied in great depth and there is little understanding of the help-seeking in respect of persons experiencing a first psychotic episode. This is supported by the findings of a review of 89 studies in this area by Lincoln & McGorry (1995).

1.7 The general process of help seeking

As previously stated in section 1.3., there is controversy regarding the appropriateness of schizophrenia as a diagnosis and whether or not it should be regarded as a mental ‘illness’. However the concept of ‘illness’ is commonly used by relatives and lay people in their attempts to understand the behavioural and personality changes associated with ‘schizophrenia’. Therefore, in order to understand the factors which influence help seeking in schizophrenia, it seems important to first look at the literature regarding help seeking for illness in general terms and then see if this may be applied to help seeking in schizophrenia.

1.7.1 Help seeking and health behaviour models

A variety of factors have been found to account for individual differences in the decision to engage in general health-promoting behaviour (Conner and Norman, 1998). In a review of over fourteen different health behaviour models, Cummings, Becker and Maile (1980) managed to combine all possible factors into six distinct categories. These were:

1. Social network characteristics
2. Attitudes to health care (i.e. beliefs about quality and benefits of treatment)
3. Perceptions of ‘illness’ threat (i.e. beliefs about individual susceptibility to illness)
4. Knowledge about ‘illness’
5. Accessibility of health care services
6. Demographic factors

Some of these factors can be illustrated by the health behaviour model known as the Theory of Planned Behaviour (Ajzen, 1991). This model suggests that intention to carry out an action (e.g. consulting a doctor) is determined by three sets of factors: Attitudes to health care; Subjective norms (a person’s beliefs about whether significant others think he or she should engage in the behaviour); Perceived behavioural control (the individual’s perception of the extent to which performance of the action is easy or difficult). Individuals are likely, therefore, to follow a particular help seeking action (e.g. consulting a doctor) if they believe that the action will lead to outcomes which they value, if they feel that they have the necessary resources and opportunities to perform the action, and if they believe that people whose views they value think they should carry out the action (Conner & Sparks, 1998).

This last point, in particular, links to some extent with the concept of ‘lay referral systems’ (Freidson, 1970). This concept suggests that people naturally use their friends and relatives as ‘lay consultants’ when they perceive themselves to be ill. If the lay system agrees and supports the notion of illness, then the need for health care is acknowledged and help-seeking is organised in some way. Zola (1973) found ‘lay referrals’ to be one of the key triggers of medical consultations. However, large lay referral systems have been found to inhibit medical consultations by denying and normalising symptoms (Alonzo, 1980), possibly because attempts are made to maintain people within the informal network (Horwitz, 1978). Frude (1991) points out that before a reliable diagnosis has been established the family may attempt to make its own diagnosis and assess the likely seriousness of the problem. Influences on those judgements include experience of previous illness, formal education, the media and myths. It is also likely that one family member will have more influence than others and mothers are generally credited with the most understanding.

1.7.2 Limitations of the above models

The major limitation of all these models is their individualistic nature. All the models are based upon the premise that the individual will act as the central agent of health promoting behaviour. This, in turn, requires the individual to conceptualise themselves as ‘ill’ or unhealthy.

In the case of schizophrenia, it is very common that the person is unaware of the changes in their thinking and behaviour or, if they are, will not regard the changes to be related to ‘illness’ or mental disorder. The person is therefore unlikely to conceptualise themselves as ‘ill’ and therefore unlikely to seek help from health care services.

1.8 The process of help seeking in schizophrenia

1.8.1 Lay understanding and representation of mental disorders

A study by Rogers and Pilgrim (1997) found that for various reasons people prefer to manage emotional difficulties within the family rather than seek professional help. These reasons included:

1. Not wanting to make a 'big deal' out of mental health problems
2. Professionals were not seen as being able to provide emotional support.
3. The costs of seeking help outside of the family outweighed the benefits i.e. the loss of face experienced might make things worse.

It seems, therefore, that people only visit professionals for help with emotional difficulties when they and their family, and possibly extended network, cannot provide a suitable explanation or reassurance for the condition or find they can no longer cope.

It has also been suggested that there is a considerable difference in the ways professionals and lay people comprehend mental health problems and their treatment (Barnes and Wistow, 1995). It has been suggested that the greater the difference, then the greater the dissatisfaction with service delivery and other aspects of client-professional relationship. It seems, therefore, that this may influence the effectiveness of help seeking in schizophrenia because of the potential difficulty lay people may find in explaining their concerns to professionals and others, in an effective way.

1.8.2 Pathways to psychiatric care

In the extensive research of Goldberg and Huxley (1988), pathways to psychiatric care have been traced, and it is suggested that there are three filters through which people pass in order to reach specialist psychiatric services:

1. The person's decision to seek help;
2. Recognition by the GP of mental health difficulties;
3. Referral to specialist psychiatric services.

The models set out in the section 1.7, relate primarily to the first filter in Goldberg and Huxley's model, as they are concerned with the individual's decision to consult professional health care services. However, the Goldberg and Huxley filter model seems to neglect that people with a severe mental disorder, such as schizophrenia, are often unable or unwilling to seek help for themselves due to the unique features of the disorder (e.g. persecutory or paranoid ideation; social withdrawal/anxiety and lack of motivation) (Hourani & Khalt, 1986).

So how do people who are unwilling or unable to seek help for their difficulties enter into the pathway for psychiatric care? One way is through a formal or informal 'referral' by a family member.

1.8.3 The family as a referrer

Rhi, et al.(1995) conducted a study which looked at health care seeking behaviours of people with schizophrenia. They found that the major decision to seek help for psychosis was made by the person themselves in only 2 percent of cases. 65 percent of the decisions were made by parents and 17 percent by spouse.

It seems, however, that in the very early stages of schizophrenia people do make some help-seeking attempts (40 percent) but as the disorder progresses these decrease and in the later stages families increasingly tend to seek help on the person's behalf (McGorry, Edwards, Mihalopoulos, Harrigan & Jackson, 1996). Therefore as the disorder progresses the family are more likely to take over the role of help seeker. These figures could suggest that either early self referrals are largely ineffectual or at that time the symptoms of schizophrenia are not evident to, or recognised by, the professional consulted (usually the GP).

Despite these findings, however, there is no clear evidence as to how strongly and in what ways the family influences the help seeking process (Vaglum, 1996). As the models referred to in section 1.7 relate to self-referral, it is not clear to what extent these models will apply to referral by a family member. This study has, therefore, chosen to focus on the family's experience of the prodromal phase of schizophrenia in an attempt to illuminate this process.

1.9 The family's position

1.9.1 The ongoing role of the family

As a result of the National Health Service and Community Care Act (1990) the majority of people with schizophrenia return to live in the community following discharge from hospital, with over 50 percent going back to live with their families (MacMillan et al., 1986). A majority of those not living with family still have a substantial amount of regular contact.

The family has been shown to play an important part in the management of schizophrenia after the first episode (MacCarthy, Kuipers, Hurry, Harper & LeSage, 1989; Tarrier et al., 1989). There has also been work on how the family copes with the burden of caring for a mentally ill relative (Leff, Kuipers & Lam, 1991; Barrowclough & Tarrier, 1994) and the support they need in order to do this (Shepherd, Murray and Muijen, 1994).

It is unclear, however, whether this work can be generalised to families in the early stages of schizophrenia. Studies have demonstrated that the quality of the caring relationship changes within the first year after first-episode psychosis, mainly in respect of EE increasing and having a stronger effect (MacMillan, Gold, Crown, Johnson & Johnstone 1986). With this in mind, there has been relatively little work looking at the experience of relatives coping with a family member during the initial prodrome of emerging schizophrenia, before they are able to access services.

1.9.2 The experiences of families

During the prodromal period it has been noted clinically that relatives of people with schizophrenia experience extreme distress. This distress seems to be related to a number of issues:

(i) Frustrations during help seeking

Taking on the responsibility of seeking help for another person can be difficult and stressful. The task of seeking help is rarely straightforward and may be frustrated by others (e.g. sufferer, other family members, GP, psychiatric services) or lack of knowledge of services.

ii) Lack of certainty

It has been suggested that prolonged ambiguity about the nature or seriousness of a disorder places stress on family members and family relationships (Frude, 1991).

iii) Impact of the person's behaviour

Atkinson & Coia (1995) suggest that the strange behaviour of a person with schizophrenia is a 'new experience' that has to be understood and responded to. The emotional impact of such behaviour on relatives, however, continues to be underestimated and this lack of acknowledgement may also feed into relatives'

distress. Grief and anxiety at seeing a loved one so disturbed may also contribute to distress.

Of course this distress may simply be a reflection of bad experiences. However it seems important to acknowledge the extreme distress families endure as it may act as an impediment to referral or indeed create another psychiatric population in its own right.

1.10 Gender differences

It is apparent from various research, that gender may also affect the help seeking process.

1.10.1 Help seeking

It has consistently been found that women are more likely than men to seek help for themselves in relation to mental health problems (Weissman & Klerman, 1977). In particular women are more likely than men to recognise perceived psychiatric problems, discuss these problems with other people and to enter treatment voluntarily (Horwitz, 1977).

It has also been noted that women are twice as likely to speak to others, especially female friends, about their problems (Horwitz, 1977). Husaini, Moore and Cain (1995) examined the relationship between psychiatric symptoms and the use of both formal and informal resources of help among elderly with mental health problems. They found that family physicians and clergy were used more frequently than mental health professionals. Use of clergy, friends and relatives and was more frequent in women than men. Men used other more solitary coping strategies e.g. drinking, walking.

There is also evidence that regardless of 'illness' severity, females with schizophrenia are more likely than males to view themselves as mentally ill, acknowledge their symptoms, view themselves as needing treatment, report psychological difficulties and seek treatment (Walker & Rossiter, 1990; Weyerer & Dilling, 1991).

1.10.2 Age of onset and marital status

Both later age of onset and being married (or in a stable relationship) have been found to indicate earlier and more appropriate access to health care for people with schizophrenia.

Many studies show that females have a later age of onset for schizophrenia (i.e. first symptoms and first hospitalisation) than males (Lewine, 1988), with the median age of onset in men being 25 years and 28 years for women (Hall, 1997). A recent study by Hafner & an der Heiden (1997) found that on average women develop schizophrenia 3 to 4 years later than men and show a second peak of onset around menopause. Other studies, however, have not found this difference in age of onset (Folnegovic & Folnegovic-Smalc, 1994). Compounding variables such as marital status and pre-morbid personality may go some way to explain this difference (Jablensky & Cole, 1997). Females with schizophrenia are also more likely than males, to be married and to have children (Walker, Bettes, Kain & Harvey, 1988; Test, Burke & Wallisch, 1990).

1.10.3 Family attitudes

It has also been found that family members' perceptions of males and females differ. Relatives tend to view females as more helpless, withdrawn and depressed than males, whilst males are viewed as more aggressive and threatening than females (Chu, Abi, Ackerman, Cetingok & Klein, 1989).

Walker & Lewine (1993) have proposed that the severity of 'illness' threshold for involuntary treatment is lower for males with schizophrenia than females because males are viewed as more threatening and unmanageable. They also propose that the severity of 'illness' threshold for females with schizophrenia is lower because they are more likely to acknowledge and report their psychological distress and seek treatment.

1.11 Summary

Research has shown that early intervention improves the prognosis for people with schizophrenia and furthermore, there is the suggestion that the family and the gender of the person may have an influence on the help seeking process and the delay known as 'treatment lag'.

The literature also suggests that the family have a key role to play in referral of people with schizophrenia. Although there is a considerable body of literature relating to help seeking and

the referral process in general, it is not clear how this applies to the role of the family of a person with schizophrenia. It is also suggested that various issues related to the gender of the person influence the referral process for schizophrenia.

This study explores the role of the family in help-seeking in the prodromal phase of a person's schizophrenia, in light of the more general literature on the subject of referrals, and in addition considers the effect of the gender of the person on that process.

1.12 Research Aims and Guiding Propositions

This study aimed to gain greater insight into how relatives experience the prodromal phase of the first episode of schizophrenia. In particular the study aimed to gain insight into several areas: What relatives thought and felt about their experience and how this experience impacted upon them; What the process was by which relatives decided that there was something 'wrong' with the person; What the processes were by which it was decided to seek help from professional services; What the experience was of making contact with professional services; What the influences were that gender of the person had upon the relatives' experience; How factors such as past experience of mental 'illness', influenced relatives' experience.

As the study aimed to provide an understanding of whether the gender of the person impacted upon the relatives' experience, the study contrasted the experiences of two different groups of relatives: one group consisting of relatives of females and the other consisting of relatives of males.

From clinical experience and the research literature the researcher expected the following findings, which acted as guiding propositions. First, that the relatives' experience would be distressing, upsetting and frustrating. Secondly, relatives would have little understanding about what was happening to the person and that they would decide something was wrong only when very clear 'symptoms' emerged. Thirdly, the process of seeking help would be frustrating and that the experience of professionals would be mostly negative. Fourthly, knowledge of mental 'illness' would facilitate help seeking. Fifthly, the process of help seeking would be facilitated, and the experience less distressing for relatives, if the person with schizophrenia was female.

1.13 Research Questions

The following questions were derived from the research aims and guiding propositions and helped to guide the schedule for the semi-structured interview.

- 1) What did relatives think and feel about their experience?
- 2) How did the relatives' experience impact upon them?
- 3) What was the process by which relatives decided that there was something 'wrong' with the person?
- 4) What were the processes by which it was decided to seek help from professional services?;
- 5) What was the experience of making contact with professional services?;
- 6) What were the influences that gender of the person had upon the relatives' experience?
- 7) Did factors such as past experience of mental 'illness', influence relatives' experience. In general, what were the main factors influencing the relatives' experience?

Having formed the research aims, guiding propositions and research questions it was, therefore, important to carefully consider a methodology that would be most appropriate to address these. Choice of methodology is discussed below.

1.14 Choosing an appropriate methodology

In order to accomplish the above research aims and address the research questions it was important to choose an appropriate methodology which could give great enough scope to investigate the ideas as fully as possible. On a pragmatic basis, it has been argued (Bryman, 1988; Marshall, Powell & Lloyd, 1996) that the methodology chosen needs to be driven by the research questions posed. In this study a qualitative methodology, Grounded Theory (Glaser & Strauss, 1967), was chosen for reasons discussed below.

1.14.1 A qualitative methodology

The debate between qualitative and quantitative research has been highlighted because of the different philosophies and traditions behind them. Quantitative research methods, on the one hand, have emerged from a positivist tradition and qualitative research methods, on the other hand, have emerged from an 'interpretative' tradition.

The positivist paradigm emphasises universal laws of cause and effect and assumes that reality consists of a world of objectively defined facts. In practical terms, hypothetico-deductive methods are used to test a prior theory and so produce quantifiable results. The interpretative paradigm, however, emphasises that knowledge is socially constructed, rather than reflecting the world as it 'exists'. The search is therefore for meaning and understanding rather than for abstract, universal laws and so results are qualitative in nature. In particular with qualitative methods the issues of validity, reliability and generalisability are different to those considered in quantitative methods and should not be judged according to a positivist paradigm (Smith, 1996a).

In an article by Smith (1996b) qualitative approaches were defined as "generally being concerned with exploring, understanding and describing the personal and social experiences of participants and trying to capture the meanings that particular phenomena hold for them". In this way the aims of qualitative methods enable us to understand a person's perception of the world in a fuller, richer way rather than test a preconceived hypothesis. On a pragmatic level, qualitative methods are therefore most appropriate when the topic under investigation is complex, novel or under-researched, and when there is concern with understanding the processes not measuring outcomes.

However, when considering qualitative methods on an epistemological level, it is the search for meaning rather than the imposing of a meaning which is fundamental (Henwood & Pidgeon, 1992). Research within a psychology and/or mental health setting needs therefore to be sensitive to people's own understandings as seen in their local frames of reference or their own 'socially situated phenomenal worlds' (Henwood & Pidgeon, 1995). Nicolson (1995) underlines this need by arguing for more subjective 'what it feels like' research to compliment and augment the vast array of more objective experimental and 'confirmational' research.

As the aim of the present study was to explore the experience of relatives at an in-depth level without direction from a testable hypothesis, a qualitative method seemed best suited to accommodate these needs.

1.14.2 Grounded Theory

Grounded Theory is a qualitative methodology that uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon (Strauss & Corbin, 1990). Data are not fitted into already existing codes and categories but instead codes and categories are allowed to emerge from the data. The coding schemes, categories, themes and theory are, therefore, all built from the data. In this way theory is generated in a systematic way but is still 'grounded' in the data, thus producing a theory that is faithful to and illuminates the area under study. Issues of reliability and validity are addressed by rigorous procedures which allow researchers to check, refine and develop their ideas and intuitions about the data (Charmaz, 1995)

Grounded theory was chosen primarily because of its ability to capture as much of the complexity in the data as possible. By showing action and change, it allows a theory to emerge that is conceptually dense but also has specificity. This was an important part of the researcher's aims.

2. Method

2.1 Design

The study was a within and between participants design, exploring the experiences of relatives of people with schizophrenia. A comparison was made between the experiences of relatives of women and relatives of men. A semi-structured interview was used to explore the research questions.

2.2 Participants

Two groups of eight participants were recruited. One group comprised of relatives of women with schizophrenia. The other group was comprised of relatives of men with schizophrenia.

2.2.1 Inclusion Criteria

Inclusion was based on two criteria. First, the client had to have a diagnosis of some form of schizophrenia or schizoaffective disorder, according to ICD-10. The client also needed to have experienced their initial episode of schizophrenia within the last fifteen years. This was to ensure that, as far as possible, experiences could be recalled accurately and were still fairly relevant to current services. Secondly, the participating relative had to have been in contact, with the client at the time of the initial episode of schizophrenia. This was to ensure that experiences were recalled at firsthand.

2.2.2 Characteristics of the Participants

Participant details are summarised in the following tables:

Table 1: Participant Details- Relatives of women with schizophrenia

<i>Participant</i>	<i>Participant's relationship to the person</i>	<i>Age of person</i>	<i>Person's Diagnosis</i>	<i>Length of 'illness'</i>
1	Mother	27	Paranoid Schizophrenia	8 months
2	Mother	33	Paranoid Schizophrenia	12 years
3	Mother	22	Paranoid Schizophrenia	3 ½ years
4	Mother	28	Paranoid Schizophrenia	6 years
5	Husband	30	Schizophrenia, Unspecified	2 ½ years
6	Mother	18	Schizophrenia, Unspecified	5 years
7	Mother	28	Schizophrenia, Unspecified	4 years
8	Father	18	Schizophrenia, Unspecified	5 years

Table 2: Participant Details- Relatives of men with schizophrenia

<i>Participant</i>	<i>Participant's relationship to the person</i>	<i>Age of person</i>	<i>Person's Diagnosis</i>	<i>Length of 'illness'</i>
9	Mother	29	Undifferentiated, Schizophrenia	8 months
10	Mother	21	Undifferentiated Schizophrenia	1 ½ years
11	Mother	34	Undifferentiated Schizophrenia	10 years
12	Father	34	Schizoaffective Disorder, Unspecified	15 years
13	Mother	26	Schizophrenia, Unspecified	4 years
14	Mother	39	Schizophrenia, Unspecified	8 years
15	Sister	35	Schizophrenia, Unspecified	9 years
16	Mother	40	Schizophrenia, Unspecified	12 years

2.3 The interview schedule

2.3.1 Development and description

A semi-structured interview schedule of open-ended questions was created. The interview questions were initially based upon an in-depth literature review and the previous knowledge of the research area by the researcher. They were then further developed through discussion with the research supervisor and various professionals colleagues. Various general questions were included if clarification or exploration of issues were necessary. Reflective feedback was also used to confirm understanding.

An initial pilot of the interview was undertaken with a professional colleague role-playing a relative of a client they knew well. The format and questions were altered slightly according

to the feedback from both colleague and researcher (Appendix 1). A second pilot of the semi-structured interview was then carried out with a relative and no further changes were deemed necessary.

2.3.2 Outline of the interview schedule

A brief outline of the interview is presented below. For the actual schedule used, the reader is referred to Appendix 1.

Section A: Background and general information

This section aimed to gain a broad picture of the situation. It also served an introductory function by allowing relatives to ‘tell their story’ as they saw it. This enabled the researcher to find natural ‘leads’ into the areas of interest for the study.

Section B: Relative’s knowledge of mental ‘illness’

This section inquired about relatives’ experiences of, and thoughts and feelings towards, mental ‘illness’ and schizophrenia. This was focused on the time before the person was diagnosed with schizophrenia.

Section C: Process of deciding that there was something ‘wrong’

This section investigated what made relatives decide that the person was having difficulties and that something was ‘wrong’. It also investigated how relatives made sense of their experiences especially if they did not attribute the client’s difficulties to a mental disorder.

Section D: The process of seeking help

This section looked at how the relative went about seeking help for the person and how the relative decided that the client’s ‘problem’ was one that needed external intervention. In particular it looked at who relatives approached, both formally and informally, and the reception they received.

Debriefing

This section completed the interview by asking participants how they were feeling, whether they had any questions or if any areas that had not been covered. Information regarding local carers' and self-help groups would be volunteered if the researcher felt that the participants may benefit from it. Participants would be asked if they would like to assist in the future respondent validity study.

2.4 Procedures

2.4.1 Ethical considerations

Procedures were developed to ensure:

- i) People (clients) were able to make an informed choice about their relative's participation in the study;
- ii) Participants were able to make an informed choice about their own participation in the study;
- iii) Contents of the interview would be kept confidential;
- iv) Adequate support was available for participants should they become distressed during or after the interview.

The research was designed so that it followed the British Psychological Society's Ethical Principles and Guidelines (1997) and the Division of Clinical Psychology Professional Practice Guidelines (1995). The research proposal was approved by the local research ethical committee (Appendix 2).

2.4.2 Briefing Procedures

A participant information sheet (Appendix 3) was created which explained the following:

- i) Aims and purposes of the research;
- ii) What was to be expected of the participants;
- iii) That participation was voluntary and participants had the right to withdraw at any time without this influencing the client's current or future treatment;

- iv) The boundaries of confidentiality and anonymity;
- v) The researcher's contact details.

This sheet was given to all the participants prior to the interviews.

2.4.3 Procedure for recruitment

Participants were sought from one area covered by the mental health services of one Trust. All consultant psychiatrists within adult mental health were approached and permission obtained to approach their clients. Possible clients were identified from various sources including clinicians, hospital discharge records and inspection of case notes.

A list of possible clients was drawn up and a key professional identified for each client. This professional was then contacted and asked to advise whether the client would be suitable for the study (in terms of eligibility and receptivity) and the best way to approach the client in order to explain the study and ask their permission to contact a relative. In most cases an explanatory letter was sent to the key professional, which they gave to the client on their next visit. On some occasions, on the key professional's advice, direct contact was made with the client to ask their permission.

Once permission was received, a letter and participant information sheet was sent to the relative that they had nominated. This letter had a reply slip and self addressed envelope that relatives could return if they wished to participate. Once a reply slip was received, the researcher telephoned the participant to arrange an interview.

Interviews lasted approximately one hour and either took place on hospital premises or in the participants' own homes depending on the participants' wishes and/or perceived level of risk. Once the researcher was satisfied that the participant had made an informed decision to participate, a standard consent form was signed by the participant (Appendix 4). Each interview was audio-taped unless the participant requested not to be taped, in which cases the interviews were recorded by hand.

2.5 Data Management

2.5.1 Theoretical sampling

In quantitative research, random sampling is important to ensure generalizability of results. However with qualitative research, and Grounded Theory in particular, this is not necessary because the aim is not necessarily to produce generalizable results but to establish a conceptually rich, dense and contextually grounded theory (Henwood & Pidgeon, 1992). Sampling, therefore, is explicitly driven by theoretical concerns and so it is only necessary to sample cases which would confirm, challenge, extend or modify the emerging theory.

In the present study an attempt was made to employ the technique of theoretical sampling. It was hoped that data analysis and data collection could be performed concurrently in order to allow the emerging analysis to shape further data collection. However this was only possible on a small scale. The first two transcripts were analysed and the emerging concepts used to inform further interviews.

2.5.2 The analytic process

All interview transcripts were analysed according to the analytic techniques of Grounded Theory as specified by Corbin & Strauss (1990). The main technique used throughout the analysis was a 'constant comparison' method (Glaser & Strauss, 1967; Pidgeon & Henwood, 1996). This required the researcher to explore the similarities and differences in the data by constantly comparing all the emerging concepts, codes, categories, themes and theory with one another. This method aimed to ensure that full complexity and diversity of the data was explored (Henwood & Pidgeon, 1992).

As constant comparison was used, the analysis was inevitably a very fluid process, moving backwards and forwards between different levels of analysis. Overall, however, the analysis generally followed the process as detailed below.

Stage 1 Data Preparation

The first ten interviews were fully transcribed onto a computer and typewritten transcripts produced. During the initial stages of data analysis, the subsequent six interviews were

partially transcribed by selecting only the aspects of the interview that fed into or illuminated the developing analysis. This technique is suggested by Strauss & Corbin (1990) and Pidgeon & Henwood (1996) and was employed because the researcher felt that the data had become ‘saturated’ and no new information was emerging.

Stage 2 Immersion

The transcripts were read several times in order to ‘immerse’ the researcher in the data and so allow the data to become very familiar.

Stage 3 Coding

Initial open coding was undertaken to break down the data into concepts. This was done by analysing one selected transcript in depth and underlining each element which expressed a different concept or facet of the data. Each different concept or facet was given a code which was then transferred onto a file card within an indexing system. All subsequent transcripts were then analysed with reference to these and subsequent emerging codes.

Stage 4 Categorisation

By using ‘constant comparison’ and axial coding, it was possible to establish links between the basic codes and so group them in various ways. In this way more abstract subcategories were formed from the basic codes. In a similar way these subcategories were then linked and grouped together to form categories. Each category was then named and defined, and appropriate quotations were selected from the transcripts in order to illustrate each category. This phase of the analysis was supported by the use of memo writing.

Stage 5 Thematic analysis

The categories were analysed by looking for any common links, connections and/or patterns between them, whilst bearing in mind any differences or anomalies. The common connections were then identified as themes.

Stage 6 Respondent validity

Once the analysis of the categories and emergent themes had been completed a summary of this preliminary analysis was prepared. This was then posted to the 14 participants who agreed to comment on the validity of the results.

Stage 7 Theory construction

Once the above comments had been received, the last stage of analysis was undertaken. By creating links between the emergent categories and themes an attempt was made to integrate them and so construct an emerging theoretical framework. This was done by a process of selective coding whereby a core category was created and then all the other themes and categories were systematically related to it. This phase of the analysis was supported by the use of memo writing and 'flow' diagrams.

2.6 Reliability and Validity

It is as important in qualitative research as in quantitative research to address the issues of reliability and validity. However, as stated before, a qualitative study should not be judged according to the traditional criteria of quantitative research. The ways in which these issues were addressed within the current study are discussed below.

2.6.1 Respondent Validity

Within the Grounded Theory context Glaser & Strauss (1967) address the issue of validity by emphasising the need for the emerging theory to 'fit' and be recognised by the people who were studied. This was addressed in three ways. First, during interviews the researcher constantly reflected back and clarified information with participants. Secondly, at the end of the interview the researcher supplied a verbal summary of the interview to the participant which they were able to challenge or modify, if necessary. Thirdly, and most importantly, the researcher posted a summary of the preliminary analysis to 14 of the participants. These comments received were then incorporated into the final theoretical framework.

2.6.2 Auditability

There were several ways in which the current study was made auditable. All relied on the basic idea of opening up the research process to external scrutiny.

i) Audit Trail

The idea behind an audit trail (Pidgeon, 1996) is to open up the analysis so another person could later check the process of theory generation and interpretation. This was done by including all the details of code, category and theme construction in Appendix 5.

ii) Researcher reflexivity

This concept relies on the researcher being able to acknowledge their subjective influence upon the research process (Sherrard, 1997) and make explicit the researcher's understandings (Stevenson & Cooper, 1997). This was addressed by the researcher keeping a 'reflexive' journal to document such things as methodological decisions and reflections on the role of the researcher's own values and interests (Appendix 6).

iii) Externalisation of the analysis and interpretation process

This was addressed by keeping an indexing system, the ongoing writing of memos and flow diagrams plus discussions with supervisor.

2.6.3 Inter-rater reliability

To assess the accuracy of the researcher's coding and categorisation an independent rater was asked to code and categorise selected text according to the researcher's original coding system. Inter-rater agreement was calculated and the results presented in section 3.

2.6.4 Internal Coherence

Smith (1996) suggests that one of the most important ways of assessing validity of qualitative research is whether it is internally coherent. In other words, whether it presents a consistent argument and makes sense. This was addressed in two ways. First, by consulting with the participants and examining their comments. Secondly, by consulting the research supervisor and other colleagues and by checking back with relevant literature.

3. Results

3.1 Overview

The analysis produced over 250 basic codes which, using a constant comparison method (Strauss & Corbin, 1990), were grouped into 36 subcategories. Through a similar process these subcategories were grouped in a more abstract way to form categories. 12 categories were generated from the data. Using these 12 categories, a thematic analysis of the data was undertaken and 4 themes produced. The results are presented as follows.

First, similarities and differences *within* the groups are presented. Each of the 12 categories are described, highlighting the main issues. Quotations, direct from participants' transcripts, have been used to illustrate the issues raised. The text refers to tables in Appendix 5 which lists the codes and subcategories subsumed under each category.

Secondly, differences *between* the two gender groups are presented. As the majority of 'between group' findings were, in fact, the same as for 'within group' findings, only the categories showing a major difference are presented.

Thirdly, the above results are employed to address the research questions, as presented in section 1.13.

Fourthly, the four themes are presented. Each theme is briefly described.

Fifthly, the results from both the inter-rater reliability study and the respondent validity study are presented.

Throughout the results section the two groups are referred to as M group and F group. The former refers to the group of participants where the person was male and the latter refers to the group of participants where the person was female.

3.2 Within Group Analysis

Each of the 12 categories and their findings are presented below.

3.2.1 Negative Feelings

Table 5 (Appendix 5) illustrates the 10 codes and single subcategory subsumed under this category.

The whole experience of the help seeking process was marked by very strong negative emotions for the participants. Examples of feelings were: confusion, frustration, desperation, anger. Most participants experienced confusion about what was happening to the person. It seemed the sense of ‘not knowing’ was a source of distress as it left people unable to resolve their feelings:

“You’re desperate. You’re desperate because you don’t know what’s going on. We were totally confused.”

Families also expressed how much stress and strain they felt:

“There were times that I nearly cracked up and walked out altogether, washed my hands of it. A couple of times.”

3.2.2 Experience of Professionals

Tables 6-9 (Appendix 5) illustrate the 10 codes and 4 subcategories subsumed under this category.

The experiences that relatives had with professionals seemed to have an impact on how relatives felt in general. Negative experiences rather than positive experiences, at least in the early stages of schizophrenia, tended to be reported.

A main difficulty people found with primary care staff (i.e. GP) was that they were often left to cope alone with acute psychiatric difficulties:

“By about five o’clock in the morning he was at the point of collapse. He was pleading with me to take him to hospital or get him a doctor....So my husband phoned the GP. He said ‘Oh, this doesn’t justify a call out. Bring him to me at 9am in the morning’. So we were left with him in this state.”

When families felt their experience of professionals was negative, this tended to add to the family's stress and distress. Negative experiences were most often highlighted if the person was admitted to hospital. Most participants commented on how they felt excluded by professionals and that their need for information and explanation was not acknowledged:

"We were left in this dining area while the doctor went off with our daughter for about an hour, just sitting there. It was just this coldness. And together with people not explaining what was going on, we just really wanted to know what was wrong with our daughter."

Where positive experiences were mentioned this tended to help families to cope:

"I had quite a good relationship with all the nurses and that there.....They understood my shifts so I could come in any time I wanted. They were very accommodating because they understood She had such a good team. That helped a lot."

Some participants found that their relationship with the professionals changed, and often improved, over time. This seemed to be related to an increased understanding of schizophrenia and of the professionals' limitations.

Another issue highlighted strongly was that there was a lack of support and communication received from the mental health teams following discharge from hospital:

"She was kept in for six weeks then they let her out.....I had no back up . I kept saying to the social worker that I needed some help but no-one helped me.... She was back in within three months.."

Participants expressed a strong wish that in the beginning there could have been a co-ordinated service with a link person for both themselves and the person, who was easily accessible and would listen to them and take their concerns seriously. This is illustrated below:

"What we wanted most as a family was a contact person who was accessibleIf we had all been able to talk together as a family that would have made the biggest difference. All those questions you never have time to ask a doctor or a nurse. And a lot of the time no-one has the answers. Almost someone you could just phone up and say 'Why is this happening?'"

3.2.3 Knowledge

Tables 10-13 (Appendix 5) illustrate the 19 codes and 4 subcategories subsumed under this category.

It was found that most people had no, or very minimal, prior experience of mental disorder:

“No, none [experience]. Schizophrenia was just a word to me. I’d heard of people having nervous breakdowns. Sometimes people had the blues after having a baby. But that’s all I really knew. I’d never come in contact with anybody with mental illness.”

Where people did have experience within their families of either mental disorder or learning disability it did not seem helpful in the help seeking process. However it was helpful in others ways such as making it easier to process the experience:

“I’ve also got a brother with Down’s syndrome...I helped to bring him up really. I think that has helped me a lot to cope with [son]. I was used to dealing with stigma from the age of 12..... The sooner you can come to terms with things then the easier it is to get on with it.”

If people had experience of the health system from other sources (e.g. working for NHS) then this did help the help seeking process because they had more understanding of who to approach and what services they could expect:

“I went into the doctor and said ‘Look, could you please do a referral letter. There’s something wrong, she needs to see a psychiatrist’It was in the evening, he wrote a letter for me.”

With regard to prior attitude, most of the participants felt neutral or open-minded about mental disorder:

“I didn’t look down my nose at it. It’s just there was too much in my life to even think about it.”

For a proportion of participants though, especially in the early stages, schizophrenia was viewed as frightening and a ‘hopeless’ condition:

“I know this sounds stupid but I thought schizophrenia was a bit like a murderer or a bank robber.”

For some participants views about mental disorder did influence whether they sought help or not. A quote from the participant feedback illustrates this:

“Our negative fearful views on mental illness delayed, for many months, our seeking help (e.g. media images of ‘loony bins’)”

Most people wanted information about what was happening to their relative but most people, at least in the initial stages, found that they received little information from the mental health professionals. Information seemed important as a way to feel more active, more empowered and less ‘helpless’. The majority of people read or watched television in order to inform themselves:

“Now I’ve found everything out. Not from the professionals though but from reading things or the telly.”

3.2.4 Isolation

Tables 14-16 (Appendix 5) illustrate the 21 codes and 3 subcategories subsumed under this category.

There seemed to be two aspects connected with isolation. The first related to the whole experience being one which was out of the ‘norm’, beyond usual experience. This meant that people often had no idea of what they were dealing with or the best way to manage the situation. This seemed to account for much of the confusion and isolation people felt.

“If you know someone is going to die you can cope, but with mental illness you don’t know what you’re dealing with.”

The other aspect related to the level of support and understanding received from other people particularly family and friends:

“I had plenty of help. That’s when you find out who your true friends were. I had quite a few stand by me and help me out.”

“My sister was a great help. She gave me lots of help.”

However, in many cases people felt that although family were supportive they were left to cope on their own by friends:

“We just felt totally isolated. It wasn’t just a case of our daughter losing all her friends, my husband and I have one set of friends, nobody else. I’ve got just a mum and a brother. They’ve been very good.”

3.2.5 Change

Tables 17-20 (Appendix 5) illustrate the 26 codes and 4 subcategories subsumed under the category of change.

Relatives had to deal with a lot of change. This revolved around three key areas. The first were personal changes (e.g. feeling shattered, becoming more tolerant).

“Another thing that has been helpful is learning to back off. Being able to accept less than I could provide. He eats absolute rubbish but he’s all right.”

“Everything just absolutely fell apart. We were absolutely shattered.”

The second area involved change in the family. For example adapting or changing living arrangements:

“Her sister took it quite hard. They used to share this bedroom. I suppose after [name] being in hospital she thought “I don’t want [name] back in my room”. Which I could understand because it was frightening her. We were going to move but we decided to stay and we built on.”

Another example were ‘splits’ and divided loyalties between family members:

“It’s caused such a split in the family. She’s been very abusive to some of her sisters and they now won’t speak to her. They don’t want me to have anything to do with her. I can’t turn my back on her.....We were such a close family but now we are divided..”

It was found that roles within the family sometimes changed. This also included how the relationship with the person had changed (e.g. levels of independence):

“I’d come home from work and there was hell let loose there. The house was in a state and I’ll have to start doing everything. And in the end I played the main part then. I took over all together.”

The third area was related to how the experience had changed people’s lives in an overall way. This also involved the changed hopes and plans for the future, for both the relative and the person:

“We’ll never have peace of mind ever again. Life will never be the same since this happened. We thought once the children were grown up we would be on our own together, but now I worry about what will happen to him.”

3.2.6 Family Decisions and Loyalty

Tables 21-22 (Appendix 5) illustrate the 14 codes and 2 subcategories subsumed under this category.

Most people did not discuss their concerns about their relative with anyone outside of the immediate family, especially in the early stages. This seemed to be related to loyalty and respect for the person’s privacy.

“I didn’t tell the family anything about it.If anyone at all has a problem I keep it to myself and don’t discuss it.”

“We didn’t talk to anybody outside of the family. I talked it over with my husband, obviously, about the strange things that were happening with her. I also talked with my son. And my sister and her husband.”

However, particularly in later stages, for a minority it was related to the stigma of mental disorder:

“I don’t tell the neighbours or anyone my son’s diagnosis because I don’t think it’s fair. They all know him and they treat him very kindly.....He’d rather people didn’t know.”

If the decision to seek help was not made by the person then, in the main, the decision maker and the help seeker were most often the mother of the person:

“My husband and I, my mum, my brother- the four of us knew that something wasn’t right. I being her mum, I had to make the decision. My husband you can understand, he’s always been very good but he’s still the step-father. So really it was my decision to take it further to get her to the doctor.”

3.2.7 Independence versus Over-intrusiveness

Tables 23-24 (Appendix 5) illustrates the 10 codes and 2 subcategories subsumed under this category.

This issue related to how much responsibility and action the family should take in regard to the person. A lot of families had to struggle with the tension between:

- a) trying to protect, and act in the best interests of, a vulnerable person and;
- b) being over-intrusive in a person’s life.

“I was afraid to go to people. I didn’t really want to be a busy-body. I felt afraid of what he’d [the person] feel about me going.”

The nature of schizophrenia seemed to have an impact here, particularly when the person were secretive, paranoid or withdrawn. This became more complicated if the person was over 18 and unwilling to seek help:

“We had two doctors here but he flatly refused to see them, and as he flatly refused to go down to the surgery, we were told there was nothing we could do. So we were batting our heads against a brick wall.”

3.2.8 Search for an answer

Tables 25-26 (Appendix 5) illustrates the 21 codes and 2 subcategories subsumed under this category.

The ‘search for an answer’ seems to be what ‘drives’ people to seek help and to keep on trying to get help even if it is difficult. It seems a ‘nagging suspicion’ gets triggered by various changes in the person’s personality or behaviour, such as strange and illogical fears and conversations. Most participants also strongly expressed an intuitive feeling that the person was ‘not themselves’ or ‘not quite right’:

“You know something’s wrong. I mean you just know, don’t you, that there’s something not right.”

All participants expressed initial general explanations for what was happening. Many individual explanations were posited but drugs and stress were most strongly suggested.

3.2.9 Rationalisation

Tables 27-30 (Appendix 5) illustrates the 35 codes and 4 subcategories subsumed under this category.

This is the process by which people try to make sense of what is happening with their relative. The underlying notion is related to events or behaviours being somehow ‘explainable’ or ‘unexplainable’. When events or behaviours are still ‘explainable’ (e.g. teenage behaviour, stress) the drive to seek help is not very strong:

“And he’d say things as if he was talking to himself. I just thought he was talking to himself. I mean, I go round the house talking to myself.”

When behaviours start to cross over and become ‘unexplainable’ (e.g. wild mood swings, very suspicious) then people are more likely to start to look for help.

“She became very, very religious. That was the first pointer. She could actually quote the bible to you. I knew by then, especially when this religion thing caught hold, that just wasn’t right, it was awful. It really got a bit weird.”

Paranoia was highlighted by over half the participants as one of the most inexplicable things:

“We went shopping and we were standing in the aisle and all of a sudden he’d say “Bloody hell!” and I’d say “What? What’s the matter?” And he’d look at the group of people as if somebody walked in that he’d seen and I was trying to look to see if I could distinguish anybody that’s walking down towards us. He’d frighten me as if somebody was following us.”

3.2.10 Help seeking

Tables 31-36 (Appendix 5) illustrate the 42 codes and 6 subcategories subsumed under this category.

Initial contacts seemed quite informal where concerns were ‘checked out’. Initial contacts tended to involve people who were not mental health professionals (i.e. extended family, teachers, vicars, help-lines, Accident and Emergency staff).

“I was just worried because she was just not herself. I rang someone I think it was Saneline. They were absolutely hopeless..”

“We even ended up going to the local vicar because things weren’t right.”

If the family goes on to seek more help, then the GP is usually the next contact.

“I was quite worried so I made an appointment for her to go down and see the doctor that evening. I thought she was depressed.”

In most cases the GP did not refer onto further mental health professionals (e.g. psychiatrist, psychologist) straight away:

“So I went in to the GP and asked him his opinion. He just said “It’s OK. I’ve given him some melleril. Come back in 4 days.”

Continuing contact with the GP seemed to be important. A good relationship with the GP made it easier for relatives to get the help they needed:

“They had to get another doctor from the surgery and because I used to work there I knew all of them. He was quite understanding because, he knew me..... He didn’t muck about then, he knew that if I was there and I was saying these things then it must be what was going on.”

It was also noticeable that in many cases the first contacts with psychiatric services were often unsatisfactory for the family. Often families would have to be very insistent and persistent to get the care they thought was appropriate.

“Anyway, I’m afraid I just sat down. They didn’t want to take him in and I said “I’m not going home with him” and they had to get him a bed, I just sat down.”

Sometimes pressure from outside the nuclear family was needed for the family to take the first step to contact health care professionals:

“Well, she was just acting so weird. One day [name] rang up her nephew and asked him to get her some sanitary towels. Her aunt, my sister, went round to see her and saw that the house was in a filthy state. [Name] was in the nude and her daughter was all dirty.....She [sister] rang me in a horrified state.”

3.2.11 Crisis

Tables 37-38 (Appendix 5) illustrates the 10 codes and 2 subcategories subsumed under this category.

One major influence on the help seeking process was a ‘crisis’ (e.g. aggressive behaviour, suicide attempts). This was sometimes the starting point for help seeking:

“That day I went off to work and during the day [name] threw herself out of her bedroom window. My husband was home..... She’d jumped through the glass. He saw her lying all crumpled on the ground. The ambulance came and took her to hospital.”

Alternatively it may speed up an already on-going process.

“She was attacking and kicking out. She was kicking and biting my husband. I said “Right, we’ll get her down to our doctor” which we did.”

For some it was the only way that they could get anyone to listen to them or access help:

“We only got help because she rang the police to say I was holding her hostage...I’d spoken to the GP so many times and he said ‘We can’t do anything until there is a crisis’. Well, I suppose that was the crisis that had to happen.”

It was interesting to note that when the crisis involved a suicide attempt this did not necessarily result in prompting any further help, other than the initial emergency help:

“He just came home to live with my parents....We knew he was unhappy but we felt he must take responsibility for it....We never thought of it in terms of madness....My mother just tried to deal with things at home”

3.2.12 Contextual Factors

Tables 39-40 illustrate (Appendix 5) the 14 codes and 2 subcategories subsumed under this category. Two factors seemed to have a general influence over the whole process.

The first was the course of schizophrenia (i.e. whether it was slow to build up or had a sudden onset). This was linked with how easy or difficult it was for relatives to detect changes in the person and justify help seeking. With a sudden onset or crisis (sometimes following insidious onset) it was obvious that help was needed from both the perspectives of the family and the health care services. If the symptoms were vague, built up gradually or ‘came and went’ then it was less likely that relatives or health care professionals could justify the need for help.

The second was how willing, or able, the person was to be involved in the help seeking. There seemed to be three ways in which a person could be involved. The first was actively seeking help on their own behalf. If the person was active and willing to seek help this put the least strain on the relationship between the person and relative. However it did not necessarily lead to any help from health care professionals:

“He kept going back to the doctor and trying to explain how he felt. And the doctor kept saying ‘Oh, no you’re just depressed, you’ll get over it. [name] came back and said ‘Mum, I just can’t get through to him.’”

The second was being passive in the process and accounted for about half of all participants. This was when the person took no interest in seeking help. However often the person could either be encouraged by the family to seek help or would put up no objections to the family seeking help on their behalf. This put the family under some pressure with regard to the ‘independence versus intrusiveness’ dilemma highlighted in category 7.

The third was being obstructive to the process. This occurred when the person denied their symptoms and/or refused help. This was the most pressurising situation for relatives as the over-intrusiveness dilemma highlighted by category 7 was most evident. This also interfaced with professionals being unable or unwilling to see the person without their consent:

“At first she was saying that there was nothing wrong with her ‘I’m all right, there’s nothing wrong’. But we could see that there was something wrong and she wasn’t admitting it. She was defeating it all the time and it was getting worse and worse and worse.”

It was highlighted that in about a fifth of cases the manner in which the person involved themselves in help seeking changed over time.

3.3 Between Groups Analysis

3.3.1 Experience of Professionals

One of the differences between the M group and F group was the experience relatives had with professionals. The main differences occurred with the experience of GPs. The M group reported more dissatisfaction in their interactions with their GP and less faith in their GP’s ability to understand the person’s difficulties:

“The doctor came. Well, he was a useless bugger. And he said ‘Oh, well he’s a little bit depressed’. I mean, I’m his mother but I knew he was more than depressed. He said ‘Do you want to go to hospital?’ and [name] said “No”. So the doctor said “Oh, well he’ll be all right”

3.3.2 Change

Although with both groups the experience had changed their lives in various ways, there was one particular aspect that was highlighted in the F group. Of the eight females, three of them had children and this was a particular concern for the families about the effects of the experience on the children. This had thus impacted upon the family roles and responsibilities, as usually other family members had to take over child care responsibilities, sometimes permanently:

“We’ve got custody of our grandson now, her child. I’m bringing him up because she just can’t. I’m over sixty and I’m bringing up an eight year old. She comes and spends time at our house..... She’s really good with him when she’s able to.”

This issue also had an effect on the hopes and plans for the future. The F group raised particular concerns about whether the person would have children and whether the children might also be at risk from schizophrenia.

3.3.3 Family Decisions and Loyalty

This category was marked by a difference in who made the decision to seek help. In the F group the person themselves did not make a decision to actively seek help for themselves. In the M group however, over a third made an independent attempt to seek help, at least in the early stages of schizophrenia.

3.3.4 Independence versus Over-intrusiveness

The difference found in this category links with the difference found in the above category. It was found that in the M group some of the males had sought help for themselves from their GP but the family had been unaware of this.

“I didn’t know at the time, that [name] had already been to a doctor in that preceding six months. We didn’t know this until after the episode when we were searching his bedroom thinking that perhaps he was taking drugs. We came across a prescription drug.....a form of tranquilliser. So obviously [name] knew early on that he needed some help.”

3.3.5 Contextual Factors

The only contextual factor which showed a major difference between the F and M groups was how willing or able the person was to be involved in the help seeking . This linked somewhat to the differences found between groups in the categories of ‘Family Decisions and Loyalty’ and ‘Independence versus Over-intrusiveness’. The major difference between the gender groups was that the F group women were more passive in help seeking than the M group men. No women took active independent action in their help seeking whereas a third of the men did, at least in the early stages of schizophrenia. Roughly equal numbers were considered to be obstructive to the process.

3.4 Summary: Application of results to the research questions

The research questions are presented in section 1.13. The researcher wanted to stay as close to the data as possible, so data was coded and categorised without reference to the research questions. However, the emergent categories did loosely relate to the research questions, as detailed below.

The first question asked about the thoughts and feelings relatives had about their experience. Two categories: 'Negative feelings' and 'Isolation' seemed to relate most closely to this question. These categories indicated that, in the main, relatives felt frustrated, confused, angry and often somewhat isolated in their experience.

The second question asked how the experience impacted upon the relatives. This is addressed by the 'Change' category, indicating that the experience had changed them, their family and their life.

The third question asked about the process that relatives went through in order to decide that something was 'wrong' with the person. Two categories: 'Search for an answer' and 'Rationalisation' seemed applicable here. They describe how initially the relative is triggered into finding an explanation for the person's 'difference' and then, by a process of rationalisation, decides whether or not there is something 'wrong' with the person.

The fourth question asked about the process of seeking help from professional services. Three categories related to this question: 'Family decisions and Loyalty'; 'Independence versus Over-Intrusiveness'; and 'Help Seeking'. The first two categories highlighted the dilemmas that families face when trying to make a decision. The third category detailed who families approached once they had made a decision and how this process was managed.

The fifth question looked at how professional contacts were experienced by relatives, and is addressed by the 'Experience of Professionals' category. This category highlighted how poor experiences increased distress and how positive experiences helped relatives cope.

The sixth question asked how gender influenced the process. This question could be related to the 'Between groups analysis', as detailed in Section 3.3 above. This indicated that, in general, gender did not have a major influence over the process. However, one exception was that males tended to be more active in the help seeking process. This was less stressful for the

relatives and helped preserve a more positive relationship. In addition the relationships with GP were less satisfying for the M group. This could relate to the fact that although males were more active in help seeking they were not more effective.

The seventh question asked which factors had a major influence over the experience. The following categories seemed to relate to this question: 'Knowledge'; 'Crisis'; and 'Contextual Factors'. Knowledge and experience of mental disorder only seemed to have a minimal effect whereas the person's involvement in help seeking, the course of schizophrenia and crisis all had an effect.

3.5 Thematic Analysis

The following themes were generated from the data, codes and categories, as an initial step towards an integrated theoretical framework. Each theme has two or more dimensions.

3.5.1 Theme One: Understanding

The first dimension belonging to this theme is the relative's individual understanding. This is the way in which relatives provided an explanation in order to account for the changes in the person and relates to how the relative tried to make sense of their experience. Understanding seemed important as a way to reduce intense feelings such as confusion, frustration and isolation.

As few relatives had any prior experience of mental disorder, understanding was initially made more difficult and therefore became an important aspect of the process. This understanding had an impact upon whether, and when, the relative decided to take any further action with regard to the person's difficulties. For example, if the relative managed to make sense of, or 'normalise', the difficulties they did not see the need to take any further action.

The second dimension of understanding was more pervasive and acted like a current which would underlie the entire experience of the relative. This dimension described how the relative was constantly trying, often desperately, to understand what was happening with the person. The relative might seek to find understanding through their own individual thinking or reading. They may also look wider and seek understanding through discussion with family, friends, professionals within the health care system and others within the wider social and

cultural circles. Many relatives also found understanding through the media or other relatives in a similar situation.

With both dimensions, the form and intensity of understanding changed depending on the course and nature of schizophrenia. For example, if the course of schizophrenia was gradual then the need for understanding tended to be gradual. However, if there was a sudden onset or crisis then the need for understanding became intense and pressing.

3.5.2 Theme Two: Communication and Interaction

The first dimension within this theme relates to the process that occurred when relatives tried to communicate their experience. Each relative made at least some attempts at communication with others, for example, family, friends, GP, hospital staff. Certain issues such as loyalty to the person and not knowing quite what to communicate, influenced how freely relatives felt able to communicate and interact with others.

The second dimension within this theme relates to the manner and outcome of the interaction. In particular the effect of the interaction between relatives and health service professionals had a great impact on feelings. Where there was an open and free flow of information between relative and professional, feelings of isolation, confusion and frustration were lessened. Where information between relative and professional did not flow openly and freely, then relatives were not relieved of their feelings of isolation and confusion. Often this scenario would lead to increased intensity of these and other negative feelings, in particular frustration and helplessness.

With both these dimensions, but in particular the second, one factor had an overarching influence. This factor was how willing or able the person was to be involved in the help-seeking process. If the person was more active in the process then interaction within the family relationships were less pressured. If, however, the person was denying their difficulties or they refused to seek help then the process of interaction for the relative was made a great deal more difficult.

3.5.3 Theme Three: Action

The first dimension of this theme relates to the action that relatives took in response to their experiences. This involved the people that they choose to approach e.g. friends, vicar, GP, etc., and at what stage they choose to do this.

The second dimension is concerned with further action and attitudes to action. These issues were often influenced by the responses relatives received to their actions. For example, if some relatives did not get the response they hoped for following their actions, then they were cast into more confusion and so gave up their action. However, some relatives, on the other hand, choose to deal with this in a forthright manner and keep trying both the same and/or different avenues for help. Of course, most relatives followed both these courses at different times during their experiences.

Action as a theme was influenced to a great extent by two factors. The first involved how active or obstructive the person was in the process. This impacted upon how involved and responsible the relative felt in the person's life and also how much they were aware of the difficulties. The course of schizophrenia was also another strong factor, in a similar way to the first theme, a crisis prompted swift and determined action whereas a gradual build up prompted more subtle and 'checking out' action.

3.5.4 Theme Four: Difference

This is a theme that permeates through all the above themes and, in one dimension, it is what prompts all of the above. That is, it is the difference, or differences, that the person exhibits, which prompts the need for understanding, the need for communication/interaction and the need for action. The difference that the person shows may be in their behaviour, their conversation, their thinking or just in their general manner of being.

Another dimension of difference is with respect to how the family feel and respond. There is an element of feeling apart and isolated from others. A third dimension is the difference that is recognised by others, in particular the professionals that the relative comes in contact with. This is a difference that they may or may not acknowledge within the family. The fact that each family's needs and situations are different and they must be treated as such. When this is acknowledged it helps people to understand, communicate/interact and take appropriate action.

3.6 Reliability and Validity

3.6.1 Respondent Validity

After the preliminary analysis of the data, a summary was prepared of the main findings (Appendix 7) was sent to the participants for comment. Twelve participants returned their comments and a summary of these are presented in Appendix 8.

In general, respondents viewed the categories as representing their experience very accurately. However it was highlighted by two respondents that some of the positive aspects of the experience had been overlooked in relation to the categories of ‘Support’ and ‘Experience of professionals’. This highlighted to the researcher that the guiding propositions may have biased the analysis of these categories. The researcher was therefore able to use these comments to go back and review the original data and thus develop the two categories further.

3.6.2 Inter-rater reliability

An independent rater was used to check the reliability of code, subcategory and category assignment. This was done by initially selecting a transcript at random from each group. First, the rater was given a list of the 200 basic codes and asked to read the transcripts, circling any segments of the text that they felt corresponded to a basic code on the list, and to then place the number of that code against the circled text. Secondly, the same rater was then given a list of the 36 subcategories and asked to sort the 200 basic codes into these 36 subcategory headings. Thirdly the rater was given a list of the twelve categories and asked to sort the 36 subcategories into 12 categories. Indexes of code, subcategory and category agreement were calculated. Cohen’s Kappa was used, which represents the proportion of agreement between raters, corrected for chance (Hammond, 1995). This results presented in the table below showed fairly good inter-rater reliability.

Table 3: Results of inter-rater reliability study

Type of assignment	Index of agreement (calculated by Cohen’s Kappa)
Code	0.76
Subcategory	0.60
Category	0.54

4. Discussion

4.1 Overview

A theoretical framework is proposed to explain the experience of relatives during the initial stages of schizophrenia, in terms of the relatives' adjustment to the process. This theoretical framework is evaluated in light of the research data and other theoretical literature. An evaluation of the reliability and validity of the research findings is then presented along with a critique of the study in general. Implications for clinical practice and service delivery are discussed and recommendations for future research proposed.

4.2 A Proposed Theoretical Framework

A theoretical framework is proposed to explain how relatives adjust to the experience of schizophrenia in its early stages. As little difference was found between the experience of the M and F groups the theoretical framework applies to both groups unless otherwise stated.

The process of adjustment goes through four phases: 'Normality'; Explainable Difference, Inexplicable Difference, and Mental 'Illness'. These phases are not static and can inter-relate and overlap. The relative may therefore move back and forth quite freely between the phases. Sometimes relatives may 'oscillate' between two adjacent phases, before definitely moving into the next one.

During the entire process the relatives 'weigh up evidence' (i.e. consider the changes and differences in the person). In order to gauge the strength of the evidence the relative may well 'check out' or discuss concerns with other people. It is the strength of the evidence, either individually or cumulatively, that provides most of the momentum for relatives to continue progressing through the phases. Of course there are other factors which may inhibit or increase momentum at any stage. These factors may be individual to the relative themselves, such as loyalty to the person, or external to the relative, for example, accessibility of services. These factors will be discussed in more depth later in the paper. Help seeking is one of the behaviours that relatives engage in at different parts of the process and may take a different form according to the stage the relative is at.

Time taken to progress through the phases varies with each individual's experience. The process may take weeks or years. However, it seems that relatives do go through each phase even in the event of sudden onset or a crisis situation.

4.3 The Phases

4.3.1 Phase One - 'Normality'

During this phase the relative does not perceive any changes of note in the person. The person seems to be their 'normal' self. However, the relative may begin to get the first hints all is not 'quite right' with the person, but these hints in themselves, are not a cause for concern. The relative does not engage in any help seeking behaviour.

4.3.2 Phase Two - Explainable Difference

This phase is characterised by the relative perceiving the person as noticeably different. Often there is a feeling that the person is 'odd', 'not themselves', 'acting out of character'.

However, the behaviours of the person are not so unusual that they cannot be explained in a way that is acceptable to the relative. During this phase, the first signs of help seeking occur where relatives may start 'checking out' their suspicions or concerns with other people usually in an informal way, with very close family members.

As this phase progresses the relative may begin to experience difficulty in explaining all the 'strangeness' that the person is showing. It is characteristic that the relative will question what is 'normal' and look for comparisons with someone the same age as the person, often the person's siblings or friends. It is towards the end of this phase that relatives are most likely to 'check out' their suspicions or concerns with a wider circle of other people. This can still be informal (e.g. family, friends) or more formal (e.g. school teachers, vicars). During this phase it is unlikely relatives will approach health service professionals.

4.3.3 Phase Three - Inexplicable Difference

This is the phase when relatives have great difficulty explaining the person's behaviours. There is a great suspicion that something quite serious might be wrong with the person. This is when the realisation that the person needs some sort of help occurs, although often relatives

do not know what sort of help is required because they do not know what exactly is wrong. Some relatives will contact someone who has some expertise in health matters first e.g. a friend or relative who is a nurse or doctor. However, most relatives will contact their own or the person's GP in the first instance. During this phase it is common that neither the relative nor the person have any idea what the exact problems are. This may be so for the GP as well. The early stages of this phase are not often characterised by a referral to mental health services.

In the advanced stages of this phase relatives start to have serious concerns about the person. The person's behaviour has often become so bizarre and inexplicable that the relative becomes frightened of, or angry and frustrated with, the person. Often relatives will have started to suspect mental 'illness' or something antisocial, such as drugs. This is when relatives are most likely to request or demand further help from the GP. This phase is often characterised by a desperate struggle between relative, person and GP to obtain appropriate help, each exerting a positive or negative influence on the process. The person may or may not be referred onto mental health services.

4.3.4 Phase Four- Mental 'Illness'

This is when mental 'illness' is finally suspected or confirmed by the family and/or GP. It is during this phase that the majority of referrals to mental health services are made. This referral may or may not result in the person being diagnosed or being given care by mental health services. If the person is diagnosed and/or taken on by the mental health services then relatives often see this as an end to the initial help seeking process. The process of getting appropriate help is often perceived as a hard struggle. When recognition of the mental 'illness' is made and access to appropriate services obtained, relatives usually feel a great sense of relief. This is often described in terms such as 'getting the ball rolling' or 'the heavens opening'.

When a person is not diagnosed, sometimes relatives feel relief because they are reassured nothing is wrong. However, most relatives feel angry and frustrated because they already 'know' that something serious is wrong with the person. At this time they often doubt themselves and doubt medical opinion. If this is the case then the relative may start to oscillate between this phase and the last phase. In most cases, eventually the 'illness' will become diagnosed and the person will be taken on by the mental health services and so end the process of initial help seeking.

4.3.5 Resolution of the adjustment process

Relatives engage in the above process, in the main, to accomplish two primary tasks. First, to find an explanation for the person’s difficulties. Secondly, to obtain appropriate care and help for the person. However, in order for these tasks to be accomplished and for adjustment to progress smoothly with the least distress, it is proposed that the relative’s needs need to be met in four areas. These areas correspond with the four themes presented in section 3.5 and can be presented as a matrix on two dimensions: practical/emotional; and specific/general, as illustrated by Table 4 below:

Table 4: A ‘matrix’ of needs that relatives have in the early stages of schizophrenia

	Specific	General
Practical	Need for understanding (e.g. diagnosis, information on schizophrenia)	Need for action (e.g. medication for the person, community support, sectioning)
Emotional	Need for integration of ‘difference’ (e.g. exploring what schizophrenia will mean for the individual family)	Need for communication & interaction (e.g. be listened to and have concerns acknowledged)

For each family the importance of each area would differ according to their own individual circumstances. For example, it may be important for a family to have one area satisfied quickly before others can be addressed, whilst another family might need all areas to be addressed in parallel . However, in general, if the needs of the relative are met to their satisfaction in all four areas then adjustment to the process will be facilitated. If, however, needs are not met to a reasonable level in one or more of the areas, then it is suggested that adjustment becomes more problematic and so distress experienced during the process might increase.

4.4 Influences on Progression

It is proposed that progression through the phases may be influenced by the factors discussed below.

i) Sense of loyalty

If the relative has a very strong sense of loyalty to the person then this may inhibit the relative's process of 'checking out' with other people especially in the wider familial or social circle. In these cases it may be that external pressures (e.g. extended family, neighbours) provide the motivation to progress to the next phase.

ii) Person's involvement in help seeking

When the person is unwilling to seek, or accept, help then it is possible that progression may slow down between Phase Three (Inexplicable difference) and Phase Four (Mental 'illness'). The relative may find themselves in the position where health service professionals, in particular GPs, will refuse to pay a domicillary visit and/or assess the person without the person's consent. The relative may then be 'stuck' until either the person can be persuaded to accept help or until a crisis situation occurs and help can be enforced.

Another reason for this 'stuckness' may rest with the mental health professionals themselves. Often, on one assessment, it is difficult to pick up or diagnose a mental disorder. The psychiatrist often then refers back to the GP. This process may continue until mental disorder, or more specifically schizophrenia, becomes evident. This happens more often than not through a crisis situation. Relatives by this time are frustrated and very angry with the system.

iii) Relationship with the GP

If the relative has a good relationship with their or the person's GP then this helps to ease the progression from Phase Three (Inexplicable difference) and Phase Four (Mental 'illness'). In these situations the relative may be seen by the GP as a 'reliable witness' and takes the relative's concerns seriously. This is most likely when the relative works within the health service or the GP has known the family a long time. It was highlighted earlier that this may be perceived as more of a problem for relatives when the person is male. Often males have tried to seek help from their GP and this has been perceived as unsuccessful in most cases.

4.5 Evaluation and Integration of the Theoretical Framework

The aim of this section is to further evaluate and integrate the theoretical framework in light of the research data and other theoretical literature in the area. This will be done in a systematic way, progressing in terms of closeness and distance from the perspective of the relative.

4.5.1 The individual response of the relative

Throughout all the phases of the process, the individual response of the relative has a strong influence. However the individual's response is, in itself, influenced by various factors. These are discussed below.

i) Knowledge and understanding of mental disorder

From the data it can be seen that few relatives had anything more than minimal knowledge about mental disorder or schizophrenia. It could be hypothesised that if the relative had increased knowledge of mental disorder then they may have been able to pick up on and understand the signs and 'symptoms' more quickly. It would then be hypothesised that this would speed up the process up and the relatives would progress swiftly through to final phase. However, in the sample the relatives who did have some experience of schizophrenia, did not find this helpful in identifying schizophrenia in the person. Why? This might link with the problematic diagnosis of schizophrenia, in that two people with the same diagnosis may not show the same 'symptoms' or difficulties at all.

ii) Attitudes to health care

This factor is taken from the Theory of Planned Behaviour (Ajzen, 1991) and relates to the individual's beliefs about quality and benefits of treatment. This factor is pertinent throughout all the phases of the proposed theoretical framework, but particularly Phase Four (Mental 'Illness'). This factor influences what action relatives will take, where they will seek help and who they will approach. At least initially all the relatives in this sample believed that the health care they were seeking was beneficial to the person and so continued to stay within the process.

However, what if the relative did not believe in, or value, the health care which was on offer because, for example, they were from a different culture? They may therefore not seek to enter into the health care system preferring to choose an alternative route. For example, this is

illustrated by cross cultural studies which highlight the use of native or religious ‘healers’ (Gater et al., 1991). This may also be an issue if the relative becomes disillusioned with the health care that was provided. This is most likely to happen after phase four has been negotiated.

Drawbacks of considering individual health beliefs

The health belief models from which these factors are taken are based upon responses to the individual’s own health needs and not that of another person. With the help seeking model proposed above the central agent of choice and decision making is not the person themselves but rather the relative, on their behalf. The possible drawback here is not knowing whether these models are still applicable in such a situation.

iii) Adapting to change

Marris (1974) suggests adaptability to change depends on the ability to fit a new situation into past experience. In the case of schizophrenia, in the majority of cases, relatives have had little past experience of schizophrenia. It therefore seems that much of their distress could be related to feelings being left unresolved due to an inability to fit their current experience into past experience. This factor is thus most pertinent in Phases Three and Four (Inexplicable Difference and Mental ‘Illness’).

One way to enable an unusual experience to be incorporated into a person’s life is to be helped by someone else, through their knowledge and experience. Thornton, Plummer, Seeman & Littman (1981) suggest that this should be in the form of prompt support and education. For relatives then, the obvious choice is to look to the health service professionals for help. However, at least initially, this help is rarely seen to be given by the professionals. This in itself increases the distress levels in relatives even further. The relatives may then take alternative action to get the help they need, for example gathering literature and reading to inform themselves, joining support groups or relying on friends and family for help.

4.5.2 The Family and their influence

Throughout all the phases of the help seeking process, the response made by the individual in the context of the family also has an influence. Phases in which the influence may be

particularly strong are highlighted. Some ways in which this influence may be understood are discussed below.

i) Containment within the family

This issue is most pertinent during Phases Two and Three (Explainable Difference and Inexplicable Difference). This is the time when the relative is ‘checking out’ with their close family members and gathering ‘evidence’ about what is going on and deciding whether to seek help. The current research data showed that, at least initially, the majority of relatives kept their concerns about the person within the family. An explanation for this is suggested by the results of a study by Rogers and Pilgrim (1997) who found that for various reasons people prefer to manage emotional difficulties within the family rather than seek professional help.

ii) Normalising the difficulties

This issue is particularly relevant to Phases Three and Four (Inexplicable difference and Mental ‘Illness’) when the relative is deciding whether to seek help for the person. The literature shows (Horwitz, 1978) that families generally attempt to maintain individuals with difficulties within an informal network. This was reflected, at least in some way, in the data of the current study. This idea was also considered by Salloway & Dillon (1973) who found that family networks, particularly large ones, inhibited medical consultations. This was because they either normalised or denied symptoms (Alonzo, 1980). However, results of a study by Scambler, Scambler & Craig (1981) contradict the above findings by suggesting that the process of intense discussion of symptoms within families actually prompted referrals to GPs.

4.5.3 The wider social and community circle

The wider social circle would include extended family, friends and other lay people encountered in a social or community setting. Throughout all the phases of the process, the response made by the individual in the context of the wider social and community setting also has an influence. Some ways in which this may be understood are discussed below.

i) Lay referral systems

Lay referral systems (Freidson, 1970) suggest that people naturally use their friends and relatives as 'lay consultants' when they perceive themselves to be ill. From the data it is suggested that most participants used some sort of lay referral system before they approached the health service system. Although lay systems, in the above context, are applied to the individual's decision to seek help for themselves it would seem likely that this lay system would resemble, at least structurally, that which the relative would use if seeking help on their own behalf.

ii) Normative Experiences

In a study by Norbeck, Chafetz, Skodol-Wilson & Weiss (1991) it was found that the carers of mentally 'ill' relatives were set apart from other carers as their experience was not a normative one which carries social approval. This would imply that the carers in the Norbeck et al. (1991) study felt isolated and possibly stigmatised.

From the data in the current study it was highlighted that one of the key issues for relatives was the isolation and 'difference' they felt. If connections can be made with the notion of lay systems, as above, then one explanation for these feelings could be that relatives and carers find that they have few or no peers who had experienced similar events and so no-one who could offer appropriate 'lay' help and advice. This in itself would lead them to feel isolated in their experience. In particular, if indeed mental 'illness' is not socially approved of as suggested in the Norbeck study, then it is possible that people in the wider social networks will be less willing to offer help and support in these situations.

4.5.4 Health Service System

Throughout all the phases of the help seeking process, the response made by the individual in the context of the health service system also has an influence.

It has been noted in this research data and the literature (e.g. Thornton et al., 1981), that there is a difference between the information and explanations that mental health professionals provide and that which relatives want and need. Possible explanations are discussed below.

i) Medical model and the lay belief interaction

One suggestion is that professionals are not giving families the 'right' type of information. Williams & Popay (1994) suggest that there is a mismatch between what relatives need in terms of explanation and information about a person's 'illness' and what the medical model is actually able to provide. When relatives ask for information and explanation, they may be asking really quite fundamental questions about how the experience is related to themselves as an individual and within a family context. The medical model is only able to provide this information in an general way, not in the applied way that relatives may need. This may go some way to explain why relatives feel so dissatisfied with the information given to them. It may also explain why relatives feel they are not listened to or their needs met appropriately. This may also connect with the way in which relatives construct what is helpful (Delin, Delin & Bassett, 1996). This issue would be most pertinent in phases Three and Four (Inexplicable Difference and Mental 'Illness') when relatives are seeking help from professional sources.

ii) Addressing relatives' needs

In terms of the four phases described in the theoretical framework earlier (section 4.3), it is suggested that resolution occurs when the relative's four areas of need are satisfied (section 4.3.5). First, in this context, the relative's 'Need for Understanding' could be considered. In the above situation it appears that this need is satisfied when a diagnosis of schizophrenia is made. It could, therefore, be suggested that a diagnosis of schizophrenia better explains inexplicable behaviours than the discussion of symptoms, particularly given the lay understanding of the nature of emotional difficulties. This diagnosis is therefore likely to correspond with the 'illness' framework for understanding which most relatives work from and also, as in the section i) above, match their construct of what is 'helpful'. It is possible that by using a 'symptom-based' approach to 'diagnose' the person's difficulties this may feed in to the relative's and person's distress. This might be highlighted by the dissatisfaction and mistrust of GPs especially by the relative's of males who had actively sought help. It is possible that this type of diagnosis did not 'contain' the relative's need for understanding.

Secondly, the diagnosis of schizophrenia may transform the person into an 'official' patient (Atkinson & Coia, 1995). This, therefore, usually gives the person and relative a 'passport' into the mental health services. This diagnosis, because of the way in which current services are set up, often triggers the help (e.g. community mental health team support) that relatives want and so the relative's 'Need for Action' starts to become satisfied.

That is not to say that the medical model or schizophrenia diagnosis is to be preferred. Although the medical model seems to address the practical needs of the relatives very effectively (i.e. Need for Understanding and Need for Action) it seems less effective as regards the emotional needs (i.e. Need for Integration of Difference and Need for Communication/Interaction). In fact, within the medical model these seem to be overlooked. A better understanding of the relatives' process of adjustment therefore might be facilitated by drawing upon both medical and psychological models.

iii) Aetiology: Family Implications

Another suggestion is that professionals are reluctant to include families in the care of the person. Why might this be?

This could be related to the psychoanalytic literature that implicates the family in the aetiology of schizophrenia. It seems that insecure early attachments do have some influence on later psychiatric difficulties (Fonagy et al., 1996). The suggestion, in relation to schizophrenia, is that if inadequate emotional care is given to an infant, then they will not develop an ability to process their own emotions effectively. This then results in a process of splitting off and projecting of emotions in order to protect the sense of self (Frosch, 1983) and thus distorts the perception of reality.

The impact of these 'causal' theories, has been both positive and negative. On the negative side it created much guilt on the part of families and blame on the part of professionals, thereby driving a rift between them. It is possible that there is a 'hangover' from the effects of these aetiological theories in that professionals, even if not on a conscious or open level, subscribe to some of these beliefs. As a consequence, in order to protect the person, professionals may tend to keep families at as great a distance as possible.

4.5.5 Wider cultural and political issues

Throughout all the phases of the help seeking process, the response made by the individual in the context of wider cultural and political issues also has an influence. Some ways in which this may be understood are discussed below.

i) Media

Prior to the person becoming 'ill', a large proportion of the relatives in this study owed their main understanding of schizophrenia to what they had read, seen or heard in the media.

On the negative side, typically people had thought of a person with schizophrenia as dangerous or unpredictable and possibly a murderer. On the positive side, relatives had found television documentaries a source of useful information. Many relatives also referred to the portrayal of a character with schizophrenia on a popular television soap opera. Some relatives had even used this character to help explain to the person how their behaviour was seen in the family.

The effect of the media influences the awareness and understanding of all the individual, the family and the wider social circle of the relative. For example, this will have an influence on the lay system's ability to give help and advice.

ii) Availability and Accessibility of Health Care Resources

This issue is one highlighted by Cummings et al. (1980) as a factor in the decision to undertake health behaviours. If health care resources are available and accessible then people are alerted to their existence and are more likely to use them. However, whether these resources are available and accessible depends very much on the health policies promoted by the current government.

In 1992, the government White Paper 'Health of the Nation' was published which set as one of its targets to improve significantly the health and social functioning of people with mental 'illness'. The consequences of this policy has led to an increase of resources in the targeted areas.

However, despite these initiatives, the data in the current study highlighted that relatives were still isolated in their experience and that there was not adequate support, particularly following hospital discharge. These wider political issues therefore, seem to have an influence on the current help seeking framework in question, in an overall but more distant way. These issues cause a 'ripple' effect by influencing where and what services people can turn to for help and what kind of help they will receive.

4.6 Summary

A theoretical framework has been proposed to explain relatives' process of adjustment in the early stages of schizophrenia. It is suggested that four phases of adjustment occur. Various factors influence the progression through these phases. Resolution is accomplished if the relatives needs are adequately met in four areas: Understanding, Communication/Interaction, Action and Integration of Difference. The framework was evaluated according to the research data and theoretical literature.

4.7 Evaluation of the Findings

According to the criteria of reliability and validity as suggested by Pidgeon (1996) the following factors are helpful in assessing qualitative research studies. These are used to look at the reliability and validity of the present findings.

4.7.1 Auditability

As mentioned in section 2.6 earlier, the researcher used three methods (audit trail, researcher reflexivity and externalisation of the analysis and interpretation process) to make the research open to external audit. In particular the reflexive process is important as this allows the researcher's understandings and position of inquiry to be made explicit (Stevenson & Cooper, 1997). This was therefore also addressed by the researcher stating, in sections 1.1 and 1.12, the background to the study and the researcher's guiding propositions.

4.7.2 Respondent Validity

The researcher used three methods to attempt validation of the study in this way (section 2.6.1). The researcher was able to use the feedback from participants in several ways. First, feedback during the interview was used to clarify understanding. Secondly, feedback from the postal study was used to refine categories and enrich the emerging themes and theory. Thirdly, the feedback highlighted that the researcher may have analysed some of the data with a bias towards the guiding propositions. The researcher was then able to use this feedback to return to the data with new insight and re-analyse with these issues in mind.

Over-reliance on respondent validity, however, has been criticised and caution advised about taking respondent's comments at face value (Henwood & Pidgeon, 1992), particularly in respect to the inherent power imbalance within the 'researcher-researched' relationship.

4.7.3 Inter-rater reliability

Inter-rater reliability was sought in order to establish that the researcher's interpretations of the data were not idiosyncratic. A reasonably high score was obtained indicating good reliability. However, only two transcripts were analysed by one rater which limits the extent of reliability somewhat. It is possible that the index of agreement, Cohen's Kappa, could have been extended to take into account more than one independent rater and thus obtain an even more accurate estimate of reliability (Hammond, 1995).

4.7.4 Internal Coherence

This was addressed by presenting findings to participants and discussing the issues with the research supervisor and relevant clinicians. All sources supported the coherence of the research.

4.8 Evaluation of the methodology

4.8.1 Potential transferability of research findings

With qualitative research, because sampling decisions have not been made on statistical grounds, it is more useful to talk about the transferability of results rather than generalisability (Henwood & Pidgeon, 1992). This term refers, in its narrowest sense, to the applicability of the research findings to similar contexts from which they were derived. Transferability improves when findings are integrated into the theory at diverse levels of abstraction. The researcher made an attempt to make the findings transferable by evaluating the theoretical framework at several abstracted levels, detailed in section 4.5.

However, although the study was based on a specific group of relatives, the theoretical framework and 'matrix of need' produced, is at a more abstract level than the data and so does

have a degree of flexibility. This flexibility may therefore allow the findings to be more transferable and so accommodate other populations.

4.8.2 Sample Bias

In some respects the issues of sample bias links with the previous issue of transferability. The sample used in the study was biased for several reasons. First, only participants who volunteered to take part were used. Secondly, only participants who the person agreed could participate, were used. Thirdly, many people's relatives were dead, estranged, living abroad or suffered from a mental disorder themselves. This resulted in the pool from which participants could be selected being very limited.

4.8.3 Reflexivity

Trying to stay reflexive was difficult and the ability of the researcher to stay reflexive was hard to judge. Procedures to increase reflexivity were incorporated within the methodology although results from the respondent validity study showed the researcher had not been totally unbiased in the analysis. However when this was brought to the attention of the researcher it was then possible to revisit the data and use the feedback to develop the findings.

4.9 Implications for Clinical Practice and Service Delivery

It is proposed that in order to better meet the needs of relatives in the earlier stages of schizophrenia, the present 'medically' orientated mental health services could benefit from more psychological understanding. The ways in which this might be achieved are discussed below.

4.9.1 Psychology involvement at a Primary Care level

Two aspects of primary care involvement seem relevant here:

i) Information for GPs

It seems useful to inform GPs about the process that relatives follow in order to get help for a person with schizophrenia. The major difficulties that relatives found in their interactions with

GPs was that they could not access help because the person had not requested it or that the GP did not see them as a 'reliable witness' in observing changes in the person. The data in this study highlights that relatives do not go to their GP or request help with idle concerns. It has taken a process of careful weighing up before the GP is approached and so the relatives are often the best person to realise something is 'not right' with the person.

ii) Improving access to information and services

From the data it was suggested that relatives had little understanding of how to get access to mental health facilities and little opportunity to discuss their concerns in an informal way. How might this be addressed?

a) Literature

One suggestion is that leaflets and posters be available in local GP surgeries and other public places. These campaigns have been organised by associations such as MIND and NSF and have also formed part of a public campaign in Norway where help-seeking strategies of the public are trying to be developed (Johannessen, 1997). However, only one participant in the study had ever been offered a leaflet at their local surgery.

b) Informal facilities

Another suggestion is that drop-in appointments could be available with a psychologist or another mental health professional where relatives could discuss their concerns informally. From the data it was highlighted that relatives would have liked the opportunity to discuss their concerns at an early stage with someone with knowledge of mental 'illness'. At surgeries where there is a psychologist employed full time this would be feasible especially if it was advertised in an effective manner. The relatives could book themselves in or be referred by GPs.

4.9.2 Psychology involvement at a Secondary Care level

The early intervention models suggested by Birchwood et al. (1997) and Falloon, Kydd, Coverdale & Laidlaw (1996) suggest that relatives need the opportunity to have concerns discussed frankly and quickly in order to foster an optimal therapeutic alliance. It is therefore proposed that relatives would benefit from a psychological perspective at a much earlier stage in the process. However, difficulties arise when considering what sort of information can be given to relatives about schizophrenia. It is therefore difficult to know how to develop appropriate services when the current services are so constrained by the diagnosis of schizophrenia. One way that psychology might address this issue is to highlight the processes and phases of adjustment that relatives might be experiencing. This could be achieved in the following ways:

a) Psychology at first assessment

It may be useful for relatives, and the person, if psychologists are available at time of the first assessments to discuss their experiences and concerns. At this time it could be useful for the psychologist to talk with relatives about the phases of adjustment that they are going through and the areas of need that they might need addressing. Overall, the psychologist could emphasis that this is a 'normal' process which other relatives experience, to some degree.

b) Educating other mental health professionals

It might be productive to include in the training of mental health professionals, an understanding of the process of the adjustment that relatives go through, including the professional's impact upon this. This might be helpful in two ways. First, it might provide professionals with an insight into why relatives may seem to be distressed by their experience or 'over-involved' with the person. This may allow the professionals to become more objective in the situation and therefore more helpful for both relative and person. Secondly, this might enable professionals to highlight the areas of need relatives have and so help the relatives through the process.

4.10 Implications for Future Research

4.10.1 Testing out the proposed theoretical framework

As previously noted in section 4.7, the current study's findings are likely to have limited generalizability. However, it could be possible to increase generalizability, precision and the predictive capacity of the framework by more widespread and systematic theoretical sampling. This would allow for more variations and conditions to emerge or be 'discovered' and thus be built back into the theoretical framework as a way to refine and expand it.

One way to address this would be to test out the proposed 'matrix of need' (section 4.3.5) by interviewing more relatives, being careful to recruit a statistically relevant sample. The hypothesis that the general framework of adjustment is transferable could then be tested out. To further expand the research findings it could then be possible to ask relatives to generate ideas about what the needs might be in these four areas and then devise a questionnaire exploring the needs in relatives. If the framework was found to be transferable then the questionnaire could be useful to assess relatives needs.

4.10.2 Further evaluation of the study's findings

It would be further illuminating to find out how the findings would be received by the participants and associated mental health professionals. This would allow the internal coherence of the theoretical framework to be examined and possibly extended. The researcher will therefore send feedback summaries to all participants asking for their comments. The researcher also intends to feedback the results of the study individually to the mental health professionals who expressed a wish to be involved.

4.10.3 Further Research

The study raised more questions than it was able to answer. However, one area that would be interesting to investigate is the effect of diagnosis on the adjustment of relatives. It is interesting to note from the data that some of the people had approached a GP and/or psychiatrist for help and although they did not receive a diagnosis of schizophrenia, they did receive another diagnosis (e.g. depression, psychosis). However, this diagnosis often did not

bring about resolution for the relative. Why might this be? It would be interesting to see if there are differences in relatives' needs according to the 'type' of diagnosis the person receives and in what way relatives' needs are best met.

5. Conclusion

The research aimed to explore relatives' experience of seeking help for a person during the early stages of schizophrenia. By using a qualitative method, Grounded Theory, the researcher was able to bring alive the experiences of these relatives and explore the complexities and richness of their situation. From the data it has been possible to propose a tentative theoretical framework that goes some way to explain how these and maybe other relatives might adjust to their experience and the needs they might have. It would be interesting to see just how useful this framework might be for relatives in the early stages of help seeking, to see if this is what they would have liked 'in the beginning'.

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APPENDIX ONE

The Interview Schedule

1. The Original Schedule
2. The Amended Schedule

Interview Schedule: Outline of questions

A- Sociodemographics and relationship with patient

- 1. Name and form of address preferred**
- 2. What is your relation to (named patient)?**
- 3. Who lives in you household currently?**
- 4. Were you living in the same household as your relative when they first became ‘unwell’?**
 - (If yes) Who was also living in that household at that time?**
 - (If no) Where/with whom was your relative living?**
- 5. How much contact do you have with your relative now? when they first became unwell?**
- 6. How would you describe the relationship you have with your relative now? when they first became unwell?**

B- Theme One: Knowledge of Mental Illness

“I’d like to ask some questions to find out a little bit about your experineces, thoughts and feelings about mantal illness before your relative became ‘unwell’”:

- 1. What was your experience of mental illness (with friends or family) before your relative became unwell?**
- 2. What were your feelings about mental illness before your relative became unwell?**
- 3. What did you know about psychosis before your relative became unwell?**

C- Theme Two: Process of deciding there was a ‘problem’

“Now I’d like to ask you some questions about how you decided there was a ‘problem’ with your relative”:

- 1. In the early stages of your relative’s illness, what sort of things made you realise that there might be something ‘wrong’ with your relative? :**
 - How did you make sense of this?**
 - Did you understand what was happening to your relative?**
- 2. What was it that made you decide that your relative might be ‘mentally unwell’?**
- 3. How long did it take to decide that your relative might be ‘mentally unwell’ ?**
- 4. What sort of things helped you to come to this decision? :**

- Did you discuss the situation with other people (e.g. family, friends, GP)?
- Who did you go to first?
- What did they say?
- What sort of help/advice did they offer?

5. Did you find there were any difficulties telling other people about what was happening with your relative? :

- Were people willing to listen?
- Did you find it embarrassing/difficult to discuss?

D- Theme Three: The processs of seeking help

“Finally, I’d like to ask some questions about how you went about seeking help for your relative”:

1. What prompted you to seek help outside your network of family aand friends?
2. What did you know about help that might be available?
3. How did you know who to contact?
4. Who did you contact initially?:
 - What was this experience like?
 - How did you get that person/agency to listen and take notice of what you were saying?
 - What information did they take notice of?
 - What information did they not take notice of?
5. What was your first contact with psychiatric services like?

Other questions

Probes and follow-up questions will be in the form of ‘who’, ‘where’, ‘what’, ‘when’, and ‘how’.

Elaboration may be asked for if the researcher requires more information (e.g. “Could you say more about...”; “I’m not sure I understand what you mean by....”).

Interview Schedule

A- Background and general information

“What I’m interested in looking at, is the experience that relatives had of a person in their family with schizophrenia and their experience of when the person first became ‘ill’. I’d like to know how they understood that and what they thought was going on and how they initially sought help. So really I’ll leave that open to you and I’ll pick up with questions that I particularly want to ask about.”

B- Theme One: Knowledge of Mental Illness

“I’d like to ask some questions to find out a little bit about your experiences, thoughts and feelings about mental ‘illness’ before your relative became ‘unwell’”:

- 1. What was your experience of mental illness (with friends or family) before your relative became unwell?**
- 2. What were your feelings about mental illness before your relative became unwell?**
- 3. What did you know about schizophrenia before your relative became unwell?**

C- Theme Two: Process of deciding there was a ‘problem’

“Now I’d like to ask you some questions about how you decided there was a ‘problem’ with your relative”:

- 1. In the early stages of your relative’s illness, what sort of things made you realise that there might be something ‘wrong’ with your relative? :**
 - How did you make sense of this?**
 - Did you understand what was happening to your relative?**
- 2. What was it that made you decide that your relative might be ‘mentally unwell’?**
- 3. How long did it take to decide that your relative might be ‘mentally unwell’ ?**
- 4. What sort of things helped you to come to this decision? :**
 - Did you discuss the situation with other people (e.g. family, friends, GP)?**
 - Who did you go to first?**
 - What did they say?**
 - What sort of help/advice did they offer?**

5. Did you find there were any difficulties telling other people about what was happening with your relative? :

- Were people willing to listen?
- Did you find it embarrassing/difficult to discuss?

D- Theme Three: The process of seeking help

“Finally, I’d like to ask some questions about how you went about seeking help for your relative”:

1. What prompted you to seek help outside your network of family and friends?

2. What did you know about help that might be available?

3. How did you know who to contact?

4. Who did you contact initially?:

- What was this experience like?
- How did you get that person/agency to listen and take notice of what you were saying?
- What information did they take notice of?
- What information did they not take notice of?

5. What was your first contact with psychiatric services like?

Other questions

Probes and follow-up questions will be in the form of ‘who’, ‘where’, ‘what’, ‘when’, and ‘how’.

Elaboration may be asked for if the researcher requires more information (e.g. “Could you say more about...”; “I’m not sure I understand what you mean by....”).

APPENDIX TWO

Letters confirming ethics approval

1. First letter requiring amendments
2. Second letter confirming ethical approval
3. Letter of approval from the Trust Director

22 January 1998

Wendy Pearse

Dear Ms. Pearse,

***A QUALITATIVE STUDY EXPLORING THE EXPERIENCE OF DECIDING TO SEEK
HELP FOR A RELATIVE SUFFERING AN INITIAL EPISODE OF PSYCHOSIS***

PROTOCOL NO. 7/98 (Please quote in all correspondence)

At the meeting on Tuesday 20th January 1998 the Local Research Ethics Committee reviewed your application form, together with the protocol for the project, Patient Information Sheet and Consent Form.

The members of the Committee present agreed that there is no objection on ethical grounds to the proposed study whose title is given at the head of this letter, but before full ethical approval can be given, the following amendments should be made to the Patient Information Sheet:

- . Add a sentence that the patient may withdraw at any time and that their treatment will not be affected.
- . The patient should be told that you are going to approach their relative.
- . That this is confidential research and that the patient will not know what has been said.

Upon receipt of a satisfactory reply ethical approval will be forthcoming.

Yours sincerely,

DR.
CHAIRMAN
LOCAL RESEARCH ETHICS COMMITTEE

5 March 1998

Wendy Pearce

Dear Ms. Pearce,

***A QUALITATIVE STUDY EXPLORING THE EXPERIENCE OF DECIDING TO
SEEK HELP FOR A RELATIVE SUFFERING AN INITIAL EPISODE OF
PSYCHOSIS***

PROTOCOL NO. 7/98 (Please quote in all correspondence)

Thank you for your letter enclosing a revised Patient Information Sheet as requested by the Local Research Ethics Committee at their meeting on Tuesday 20th January 1998.

I am now happy with these amendments and can see no objection on ethical grounds to the proposed study whose title is given at the head of this letter. I am therefore happy to give you our approval on the understanding that you will follow the protocol as agreed.

It is your responsibility as the researcher who made the application to notify the Local Research Ethics Committee immediately you become aware of any information which could cast doubt upon the conduct, safety or an unintended outcome of the study for which approval was given.

If there are amendments which, in your opinion or opinion of your colleagues, could alter radically the nature of the study for which approval was originally given, a revised protocol should be submitted to the Committee.

You will no doubt realise that whilst the Committee has given approval for the study on ethical grounds, it is still necessary for you to obtain approval from the Chief Executive/Clinical Director of the Trust in which the work is to be carried out.

Members of the Committee would like to know the outcome of the study and therefore ask that a report or copy of results is sent to the Secretary in due course.

Yours sincerely,

DR.
CHAIRMAN
LOCAL RESEARCH ETHICS COMMITTEE

Telephone:

Our ref:
Your ref:

CONFIDENTIAL

Ms Wendy Pearce,

27 March 1998

Dear Ms Pearce,

This is to confirm that this Directorate will accept your research carried out according to the Local Research Ethics Committee.

Yours sincerely,

Dr
Consultant Psychiatrist
Clinical Director

APPENDIX THREE

Participant Information Sheet

Participant Information Sheet

Study: Exploring the experience of deciding to seek help for a relative suffering an initial episode of schizophrenia

Researcher: Wendy Pearse, Psychologist (in Clinical Training)
Psychology Services
Telephone:

This study is interested in looking at the experiences people had when a family member suffered their first episode of schizophrenia. In particular it is interested in understanding the thoughts, feelings and experiences involved when making a decision to seek help for a family member with schizophrenia. It is hoped that by gaining a better understanding of these experiences, services in the future will be able to assist people to get help more quickly for people with schizophrenia.

Participation in the study would involve one interview with the above named researcher, lasting approximately one and half hours (with a break as necessary). Participants may also be asked if they would take part in a shorter follow up session (approximately four weeks later). Involvement in the study would be entirely voluntary and participants would be able to withdraw at any time. Withdrawal from the study would not influence the current or future treatment of the family member who suffers from schizophrenia.

Participants would be approached after the family member suffering from schizophrenia has been consulted. However, all information gathered from participants would be confidential to the researcher and the family member with schizophrenia will not know what has been discussed. All identities would be protected and results would be published in such a way that no individual could be identified unless the participant consented to being identified.

If you are interested in taking part in this study please telephone the researcher on the above number or alternatively fill in the slip at the back of this sheet and return it to the researcher. Once your slip is received the researcher will contact you to arrange an interview. It would be helpful if you could reply as soon as possible (within a week). If you would like to know more about the study before agreeing to participate the researcher can be contacted on the above number. She will be happy to discuss any queries you have regarding the study and you will be under no obligation to participate.

Thank you for your time.

Yours faithfully

Wendy Pearse
Psychologist (in Clinical Training)

**Exploring the experience of deciding to seek help for a relative
suffering an initial episode of schizophrenia**

Name _____

Address _____

Telephone Number _____

*I would like to be involved in the study exploring the experience of deciding to seek
help for a relative suffering an initial episode of schizophrenia.*

Signature _____

**Please return to : Wendy Pearse
 Psychologist (in Clinical Training)
 Psychology Services**

APPENDIX FOUR

Participant Consent Form

Participant Consent Form

To be completed by all participants who fulfil the eligibility criteria

TITLE OF STUDY: Exploring the experience of deciding to seek help for a relative suffering from an initial episode of schizophrenia

Please tick box as necessary

	Yes	No
Have you read the participant information sheet?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had the opportunity to ask questions and discuss the study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you received satisfactory answers to your questions?	<input type="checkbox"/>	<input type="checkbox"/>
Have you received enough information about this study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you are free to withdraw from this study:		
-At any time	<input type="checkbox"/>	<input type="checkbox"/>
-Without having to give a good reason for withdrawing	<input type="checkbox"/>	<input type="checkbox"/>
-Without affecting your relative's future care	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to take part in this study?	<input type="checkbox"/>	<input type="checkbox"/>

Who has explained this study to you?.....

Are there any comments you wish to make?.....
.....

Signed..... Date.....

Name (in block letters).....

APPENDIX FIVE

Codes, Subcategories and Categories generated from the data

APPENDIX 5:

THE CODES, SUBCATEGORIES AND CATEGORIES GENERATED FROM THE DATA

Category 1 *Negative Feelings*

Subcategory *Relative's Feelings*

Table 5: The codes subsumed under the subcategory of 'Relative's Feelings'

Male	Female
1. Desperation (3)	1. Desperation (1)
2. Confusion/'Mixed up' (4)	2. Confusion/'Mixed up' (2)
3. Anger/Frustration (5)	3. Anger/Frustration (4)
4. Grief (2)	4. Grief (1)
5. Demoralised (1)	5. Demoralised (1)
6. Frightened (2)	6. Frightened (2)
7. Worried (1)	8. Guilt (1)
8. Guilt (2)	11. Alone (2)
9. Shame (1)	10. Coping but not mentally/Stressed (3)

Category 2 *Experience of Professionals*

Subcategory 1 *Experience with hospital staff*

Table 6: The codes subsumed under the subcategory of 'Experience with hospital staff'

Male	Female
1. No interest in family's opinions/wouldn't listen/ Dismissive (2)	1. No interest in family's opinions/ Wouldn't listen/Dismissive (5)
2. Excluded/treated like an enemy/Cold (7)	2. Excluded/treated like an enemy/ Cold (5)
3. No/little explanation of what was happening or was wrong with person (2)	3. No/little explanation of what was happening or was wrong with person (3)
4. Very harsh treatment of person (1)	7. Good relationship (1)
5. Conflicting explanations (2)	8. Initially tense then improved (1)
6. Accusative/Blaming (1)	9. Once diagnosed relationship improved (1)
7. Good relationship (1)	

Subcategory 2 *Community support*

Table 7: The codes subsumed under the subcategory of ‘Community support’

Male	Female
1. No/little support after first admission (3)	2. No/little support in general (3)
2. No/little support in general (2)	3. Left alone to cope with acute problems [GP] (1)
3. Left alone to cope with acute problems [GP] (3)	4. No explanation of situation/diagnosis/prognosis by mental health team (2)
4. No explanation of situation/diagnosis/prognosis by mental health team (2)	5. No advice about how to manage schizophrenia (3)
5. No advice about how to manage schizophrenia (3)	6. Released from hospital too soon (1)
6. Released from hospital too soon (1)	7. Good support (1)
7. Good support (1)	9. Initially little support then improved (1)
8. Good support only after diagnosis (1)	10. No practical help (1)

Subcategory 3 *Faith in mental health professionals*

Table 8: The codes subsumed under the subcategory of ‘Faith in mental health professionals’

Male	Female
1. Neglecting person/allowing person to abscond (2)	1. Neglecting person/allowing person to abscond (1)
2. Mistrust of professional opinion (2)	4. Advice inconsistent/confusing (1)
3. Disagreement over diagnosis (1)	7. Wouldn’t listen (2)
4. Advice inconsistent/confusing (2)	8. A lot of trust in professionals (1)
5. Cruel treatment of person (1)	
6. Mistrust of/ no faith in GP (3)	

Subcategory 4 *What was needed?*

Table 9: The codes subsumed under the subcategory of ‘What was needed?’

Male	Female
1. Being taken seriously (1)	1. Being taken seriously (2)
2. Being listened to (1)	2. Being listened to (3)
3. Someone to ring and ask for help (3)	3. Someone to ring and ask for help (1)
4. Having a link worker for both person and the relative to turn to (2)	4. Having a link worker for both person and the relative to turn to (2)
5. Time to talk as a family (1)	7. A private place to talk with staff (1)
6. Have the complexities of diagnosis explained (1)	8. Practical/financial help (1)

Category 3 *Knowledge*

Subcategory 1 *Past experience of mental disorder*

Table 10: The codes subsumed under the subcategory of ‘Past experience of mental ‘illness’

Male	Female
1. No past experience of mental disorder (4)	1. No past experience of mental disorder (4)
2. Minimal experience of mental disorder through family/friends (3)	2. Minimal experience of mental disorder through family/friends (2)
3. Experience of learning disability through family (1)	4. Experience of mental disorder through family/friends (2)
4. Knowledge through a leaflet (1)	5. Experience of mental disorder through nursing (1)

Subcategory 2 *Helpfulness of past experience*

Table 11: The codes subsumed under the subcategory of ‘Helpfulness of past experience’

Male	Female
1. Experience helped relative ‘come to terms’ with schizophrenia (1)	4. Experience helped relative cope in practical ways with schizophrenia (2)
2. Alerted to issues of stigma (1)	5. Allowed some understanding (1)
3. Experience didn’t help (2)	

Subcategory 3 *Knowledge of how to access help*

Table 12: The codes subsumed under the subcategory of ‘Knowledge of how to access help’

Male	Female
1. No knowledge (5)	1. No knowledge (5)
2. Some knowledge (2)	2. Some knowledge (3)
3. Knowledge from a leaflet only (1)	

Subcategory 4 *Attitude to mental disorder*

Table 13: The codes subsumed under the subcategory of ‘Attitude to mental disorder’

Male	Female
1. Never thought about it before (2)	1. Never thought about it before (2)
2. Neutral attitude (4)	2. Neutral attitude (3)
3. Fearful attitude (3)	3. Fearful attitude (4)
4. Negative media stereotype (2)	4. Negative media stereotype (2)
5. Equated with learning disability (1)	5. Would never turn away from someone (1)
6. Concerned about stigma (3)	

Category 4 *Isolation*

Subcategory 1 *Support*

Table 14: The codes subsumed under the subcategory of ‘Support’

Male	Female
1. Lack of support from professionals (4) 2. Lack of support from family (1) 3. Left to cope generally (2) 4. Lack of support from GP (2) 5. Tried to ‘shield’ rest of family (1) 6. Good support from family (4)	1. Lack of support from professionals (2) 2. Lack of support from family (2) 7. Lost friends (2) 8. Lack of support from person’s friends (2) 9. Lack of support from school/college (1) 6. Good support from family (5) 10. Good support from friends (4) 11. Good support from school/college (1)

Subcategory 2 *Experience out of the norm*

Table 15: The codes subsumed under the subcategory of ‘Experience out of the norm’

Male	Female
1. No framework within which to understand/experience out of norm (4) 2. Nothing to compare it with (1) 3. Some understanding (1)	1. No framework within which to understand/experience out of norm (2) 2. Nothing to compare it with (1) 3. Some understanding (3) 4. Nothing can prepare you (1) 5. Hard to come to terms with (1)

Subcategory 3 *Informing yourself*

Table 16: The codes subsumed under the subcategory of ‘Informing yourself’

Male	Female
1. Reading (4) 2. Television (2) 3. Through being with the person (1) 4. Didn’t (2)	1. Reading (6) 2. Television (3) 5. Support group (1)

Category 5 *Change*

Subcategory 1 *The experience changes you*

Table 17: The codes subsumed under the subcategory of ‘The experience changes you’

Male	Female
1. Constantly feeling uneasy/cautious (1) 2. Becoming more tolerant/accepting (1) 3. No peace of mind (1) 4. More anxious (1)	1. Constantly feeling uneasy/cautious (2) 5. Feeling too weak to cope (2)

Subcategory 2 *The experience changes your family*

Table 18: The codes subsumed under the subcategory of ‘The experience changes the family’

Male	Female
1. Splits in family (2) 2. Increased stress levels (4) 3. Living conditions rearranged (1) 4. Arguments about the diagnosis (1) 5. Family ‘wary’ of person (2)	1. Splits in family (2) 2. Increased stress levels (4) 3. Living conditions rearranged (2) 6. Conflicting family loyalties (2) 7. Change of family routines/roles (3) 8. Financial burden (1) 9. Effects on person’s children (2) 10. Effects on younger siblings (2)

Subcategory 3 *The experience changes your life*

Table 19: The codes subsumed under the subcategory of ‘The experience changes your life’

Male	Female
1. Intrusion at work (2) 2. Plans for own/person’s future changed (3) 3. World shattered/never the same again (3) 4. Still searching for an answer (1) 5. Not really changed (1)	1. Intrusion at work (2) 2. Plans for own/person’s future changed (2) 6. Loss of social life/friends (2) 7. Implications for future grandchildren (2)

Subcategory 4 *Changes in relationship with the person*

Table 20: The codes subsumed under the subcategory of ‘Changes in relationship with the person’

Male	Female
1. Change of relationship with person (4) 2. No major change (2) 3. Increased dependency on family (2)	1. Change of relationship with person (3) 2. No major change (1) 3. Increased dependency on family (3) 4. Relationship improved (1)

Category 6 *Family Decisions and Loyalty*

Subcategory 1 *Major Decision making*

Table 21: The codes subsumed under the subcategory of ‘Major decision making’

Male	Female
1. Made by person’s mother (3) 2. Made by person’s father (1) 3. Joint parental/family decision (2) 4. Decision made by person (3) 5. Family decisions made in later stages (1)	1. Made by person’s mother (5) 3. Joint parental/family decision (2) 6. Person encouraged by family to make help seeking decisions (1)

Subcategory 2 *Keep it in the family*

Table 22: The codes subsumed under the subcategory of ‘Keep it in the family’

Male	Female
1. Only discussed with spouse (1) 2. Only discussed with ‘close’ family (e.g. person’s siblings/grandparents) (5) 3. Consulted everyone possible (1) 4. Person didn’t want others to know (2) 5. Limited consultation because of loyalty/privacy for person (4) 6. Didn’t discuss with anyone (1)	1. Only discussed with spouse (1) 2. Only discussed with ‘close’ family (e.g. person’s siblings/grandparents) (4) 3. Consulted everyone possible (1) 5. Limited consultation because of loyalty/privacy for person (2) 7. Tried to ‘shield’ rest of family (1) 8. Consulted friends (1)

Category 7 *Independence versus Over-intrusiveness*

Subcategory 1 *Pushed out/uninformed by the person*

Table 23: The codes subsumed under the subcategory of ‘Pushed out/uninformed by the person’

Male	Female
1. Person excludes family (6) 2. Family not pushed out (2) 3. Relatives in dilemma about how much to intervene (1) 4. Person seeking help without family’s knowledge (3)	1. Person excludes family (4) 2. Family not pushed out (4) 3. Relatives in dilemma about how much to intervene (3) 5. Family guilty because should have got more involved (1)

Subcategory 2 *Betrayal/Intrusion on person’s life*

Table 24: The codes subsumed under the subcategory of ‘Betrayal/Intrusion on person’s life’

Male	Female
1. Torn between ‘leaving person to it’ and carrying on helping (2) 2. Balancing respecting privacy and getting enough information to help (4) 3. Feeling of betrayal when insisting on treatment (e.g. sectioning) (3) 4. Person over eighteen and doesn’t want help (2) 5. Didn’t feel had the right to intrude (1)	1. Torn between ‘leaving person to it’ and carrying on helping (3) 2. Balancing respecting privacy and getting enough information to help (3) 3. Feeling of betrayal when insisting on treatment (e.g. sectioning) (1) 4. Person over eighteen and doesn’t want help (1)

Category 8 *Search for an answer*

Subcategory 1 *Nagging Suspicion*

Table 25: The codes subsumed under the subcategory of ‘Nagging Suspicion’

Male	Female
1. Not ‘normal self’(e.g. forgetfulness) (1)	1. Not ‘normal self’(e.g. forgetfulness) (2)
2. Strange/illogical fears (1)	2. Strange/illogical fears (2)
3. Sixth sense/vague unease/ Something just ‘not quite right’ (5)	3. Sixth sense/vague unease/ Something just ‘not quite right’ (1)
4. Strange/illogical conversations (1)	7. Acting ‘out of character’ (3)
5. Increasing agitation/anxiety (1)	8. Illogical anger (1)
6. Difficulties at school (1)	9. Withdrawal (2)

Subcategory 2 *Initial explanations*

Table 26: The codes subsumed under the subcategory of ‘Initial explanations’

Male	Female
1. Stress/Over-doing it (3)	1. Stress (1)
2. Drugs (4)	2. Drugs (1)
3. Teenage behaviour (1)	3. Teenage behaviour (1)
4. Personality/Temperament (1)	4. Personality/Temperament (1)
5. Depression (1)	8. Hormonal changes (2)
6. In trouble (2)	9. Abuse by partner (1)
7. Fed up with job (1)	10. Parents divorce (2)
	11. Past physical/emotional trauma (2)
	12. Concerns about adoption (1)

Category 9 ***Rationalisation***

Subcategory 1 ***First unexplainable strangeness***

Table 27: The codes subsumed under the subcategory of ‘First unexplainable strangeness’

Male	Female
1. Religious delusions (1) 2. Paranoia (e.g. phoned police to report intruders, watching people strangely) (2) 3. Just not themselves (1) 4. Lots of little but unusual things (e.g. wandering off) (3) 5. Illogical fears about Nazis (1) 6. Verbally aggressive (1) 7. ‘More than miserable’ (1)	1. Religious delusions (1) 2. Paranoia (e.g. phoned police to report intruders, watching people strangely) (6) 3. Just not themselves (2) 9. Person didn’t respond to usual strategies to cheer her (1) 10. Wild moods (1) 11. Illogical actions (1)

Subcategory 2 ***Explainable strangeness***

Table 28: The codes subsumed under the subcategory of ‘Explainable strangeness’

Male	Female
1. Talking to self (‘I do it’) (1) 2. Anxiety (threatened by someone/money worries/lost job) (3) 3. Saying illogical things (stress) (1) 4. Headaches (needs glasses) (1) 5. Reversed day and night (stress, drugs) (1) 6. Miserable (depressed) (2) 7. Reverted to a child (depressed) (1)	8. Withdrawal (depression /growing up) (2) 9. Out of character (abuse from boyfriend) (1) 10. Forgetful (lazy) (1) 11. Mood swings (women’s troubles/teenage behaviour) (2) 12. Working very hard (college pressure) (1) 13. Difficult at school (reaction to parents divorce) (1)

Subcategory 3 ***Excessive/Intolerable/Aggressive behaviour***

Table 29: The codes subsumed under the subcategory of ‘Excessive/Intolerable behaviour’

Male	Female
1. Threatening/aggressive behaviour (1) 2. Out of control (1) 3. Religious Delusion (1) 4. Aggressive/Bad language (2) 5. Highly anxious (3) 6. Smashing household objects (1) 7. Hurting self (1) 8. Becoming a danger (1)	1. Threatening/aggressive behaviour (2) 2. Out of control (1) 3. Religious Delusion (1) 5. Highly anxious (1) 9. Behaviour always ‘one step more’ than normal (1)

Subcategory 4 ***Comparison with family norm***

Table 30: The codes subsumed under the subcategory of ‘Comparison with family norm’

Male	Female
1. Compare with person’s siblings (3)	1. Compare with person’s siblings (2) 2. Compare with person’s friends (2)

Category 10 *Help seeking*

Subcategory 1 *Initial help seeking*

Table 31: The codes subsumed under the subcategory of ‘Initial help seeking’

Male	Female
1. Accident and Emergency (1) 2. Tutor at school/university (3) 3. Relative who was a doctor (1) 4. Social Services (1)	1. Accident and Emergency (1) 2. Tutor at school/university (3) 5. Vicar (1) 6. Friends of person (1) 7. Work colleague (1) 8. Rang Saneline/MIND helpline (1)

Subcategory 2 *First professional contact*

Table 32: The codes subsumed under the subcategory of ‘First professional contact’

Male	Female
1. Person’s GP (unsuccessful) (3) 2. Person’s GP(successful) (4) 3. Private psychiatrist (1)	1. Person’s GP (unsuccessful) (2) 2. Person’s GP(successful) (5) 4. Child Guidance clinic (unsuccessful) (1)

Subcategory 3 *Second professional contact (by referral)*

Table 33: The codes subsumed under the subcategory of ‘Second professional contact (by referral)’

Male	Female
1. Psychiatrist (unsuccessful) (3) 2. Psychiatrist (successful) (1)	1. Psychiatrist (unsuccessful) (2) 2. Psychiatrist (successful) (1) 3. Psychologist (unsuccessful)(1) 4. Community psychiatric nurse (successful) (1)

Subcategory 4 *Relationship with GP*

Table 34: The codes subsumed under the subcategory of ‘Relationship with GP’

Male	Female
1. GP not involved (1) 2. GP minimised the difficulties (2) 3. Reasonable but relative had to persist (2) 4. Variable within the practice (2) 5. GP refused to visit (2) 6. Very good with person (2)	1. GP not involved (1) 2. GP minimised the difficulties (1) 7. Facilitated process/referrals, etc. (3) 8. GP refused to discuss anything with family (2) 9. Relative knew GP (2)

Subcategory 5 *Family insist on action*

Table 35: The codes subsumed under the subcategory of ‘Family insist on action’

Male	Female
1. Didn't insist (4) 2. Family 'beg' for help (2) 3. Family disagree with care so remove person (1) 4. Relative sat down and wouldn't move (1) 5. Family insist on medication (1)	1. Didn't insist (4) 6. Family don't insist until crisis (2) 7. Family have to get to desperation point (2)

Subcategory 6 *Pressure from outside the nuclear family*

Table 36: The codes subsumed under the subcategory of ‘Pressure from outside the nuclear family’

Male	Female
1. Person's brother (1) 2. Person's work (1) 3. University tutor (1)	4. Person's sister (1) 5. Hint from mother of person's friend (1) 6. Health visitor made referral (1) 7. Flatmate of person (1) 8. Boyfriend of person (1)

Category 11 *Progression*

Subcategory 1 *Suicide attempts*

Table 37: The codes subsumed under the subcategory of ‘Suicide attempts’

Male	Female
1. Prompted immediate help (1) 2. Didn't prompt help (2)	1. Prompted immediate help (2) 2. Didn't prompt help (2) 3. Start of process (2) 4. Point of access in ongoing process (2)

Subcategory 2 *Crisis*

Table 38: The codes subsumed under the subcategory of ‘Crisis’

Male	Female
1. Only way to get someone to listen or to get help (1) 2. Suicide attempt (1) 3. Acutely psychotic (2) 4. Physical/mental collapse (2) 5. Road accident/car crash (2) 6. Arrested (1)	1. Only way to get someone to listen or to get help (2) 2. Suicide attempt (2) 3. Acutely psychotic (2) 4. Children at risk (1) 5. Physical attack on family member (2)

Category 12 *Contextual Factors*

Subcategory 1 *The course of schizophrenia*

Table 39: The codes subsumed under the subcategory of ‘The course of schizophrenia’

Male	Female
1. Gradual build up until clear symptoms (between 7 months and 1 years) (2)	1. Gradual build up until clear symptoms (between 9months and 3 years) (4)
2. Rapid onset until clear symptoms (2 mths) (1)	6. Gradual build up until crisis/aggressive behaviour (between 6 and 18 months) (3)
3. Gradual build up until crisis (2 years) (1)	7. Vague symptoms until crisis (1 week) (1)
4. Rapid build up until crisis (3 months) (1)	
5. Vague symptoms until crisis/excessive behaviour (between 1 and 3 months) (3)	

Subcategory 2 *How willing, or able, the person was to be involved in the help seeking*

Table 40: The codes subsumed under the subcategory of ‘How willing, or able, the person was to be involved in the help seeking’

Male	Female
1. Passive (took no part/interest, went for help only if family encouraged) (2)	1. Passive (took no part/interest, went for help only if family encouraged) (5)
2. Obstructive (denied symptoms &/or refused help) (2)	2. Obstructive (denied symptoms &/or refused help) (1)
3. Active (sought help on own behalf) (2)	6. Obstructive initially then Passive (1)
4. Active initially then Obstructive (1)	7. Passive initially then Obstructive (1)
5. Active initially then Passive (1)	

APPENDIX SIX

The Research Diary

Research Diary

3.7.97

Had a meeting with Lynne, my new supervisor. It's a bit confusing starting with one supervisor and then changing to another. They've both got different approaches so it's hard to know what's right or wrong or just opinion. Lynne's suggested a qualitative approach which is a bit scary but seems to be the best way to try and find out what I want to find out.

9.7.97

Went up to meet with P.G. to discuss my dissertation. I thought it might give me a wider understanding. It didn't. She was really nice, I got a cup of tea and everything. It just makes me realise how much I haven't read, how little my dissertation is (when it seems so enormous to me).

1.10.97

I'm back with Tony Lavender now supervising me. My design doesn't seem to answer the questions I'm asking. I'm keep trying to put a hypothesis into a qualitative study.

27.10.97

Meeting with senior reg. and consultant on my placement. No-one turned up for the client review so lots of time to spare to chat with me. Got loads of ideas and they were both really interested

Ideas: chain of events leading to services; where do things go 'awry'.

Talking with the medical side highlights their reluctance to suggest or diagnose schizophrenia or any type of mental disorders. Helpful to think with them about how I will define my client group, what diagnosis to consider, how long they people have been diagnosed. Helpful to think about the practicalities with people who know the service really well.

28.19.97

Supervision with my placement supervisor. More useful stuff about who to approach and when and how, etc. She's been really looking out for me and trying to find out the times for the next ethics committee.

4.11.97

I'm trying to get my ethics committee form in for December. I just can't do it. I've gone over it time and time again and something doesn't make sense. It's a bit of a stressful time at the moment. Trying to plan a wedding, move house, go to New Zealand, write an ethics proposal. That's the worst bit. I think I'll just have to stop trying to finish and head for the January committee.

29.12.97

It's a constant battle between wanting a theory and just getting on with it. Finding it hard to understand the papers on qualitative research.

Needed to give up my defences today against things I don't understand. Trying to remember that curiosity can be fun, not a burden. Trying to remember that I was once curious about

things. Now the course and everything seems to have become too much of a pressure that I just shut down against new information.

6.1.98

Really, really, really productive meeting with one of the new consultants. He cheered me up so much. He was actually interested in what I was doing. He wanted to help me. Really kind and really clear. Helped me understand some of the pitfalls I might come across. Explained all about the research he'd done into schizophrenia. It seems a bit more worth it now. I was beginning to lose the plot. I think I was forgetting how my ideas came from real people and their problems. It reminds what the point of my research is about.

14.1.98

I can't believe it. I've now met all the consultants and they were all so supportive and interested. They catch me in the corridor with queries about how things are going. They want to have the results. It feels like I can do no wrong. The only drawback is now I have to do some work.

20.2.98

Supervision with Lynne. I have to drum it into my head that I am not trying to test a hypothesis in my project. In fact I should be trying to find an emergent theory.

2.3.98

Realising that it may give a clearer picture of what is going on in the relative's experience if I consult the client. I'm finding it a struggle to get my head round the practicalities of asking permission from lots of clients especially as they may say 'no' and then what? That would bias my sample. I'm trying to decide whether to change my study from the gender comparison to the patient relative comparison.

5.4.98

Things are really starting to move now. I've done some interviews. I've transcribed and analysed my first tape. I've got a good system going now of how to contact CPNs and social workers who are involved with the client. A couple of the social workers have been exceptionally helpful, giving me names, contacting people for me. It's hard work keeping it going through. I hate being rejected by people. I'm trying to not mind so much and see it as their choice not that they are trying to ruin my research.

10.5.98

Somehow I seem to be tapping more and more desperation in people. People seem to want to tell me awful things, how awful their experience was. I know I'm asking but sometimes I don't want to hear it. It's a strange dilemma.

14.5.98- Transcribing Tapes

Not wanting to listen to the tape because it makes me so sad. Thinking how vulnerable we all are to mental illness. Thinking that, having just got married, with all the hopes of the future, that I can't bear to think of that happening to me and how the hopes would be dashed. Feeling very sorry for the participant. Feeling a bit curious why they didn't just give up. Thinking how

you must just get swept along hoping things will improve. Maybe I'm pessimistic because I've seen so many people with severe mental illness who don't seem to get better. Thinking that I wouldn't have the strength or courage to do what they've done, thinking that such little things upset me up that I just wouldn't be able to stay happy or sane in that environment.

Hearing about how patient's medication was stopped during pregnancy makes me feel very angry. Angry with the GP for not monitoring the situation more closely, knowing that she had had to stop medication for mental illness. Should have watched for signs of deterioration and not made this poor family suffer in such a way.

By page 7 beginning to get a bit fed up. Makes me think about how CPNs must feel. It's emotionally exhausting.

20.5.98 - Transcribing (Again)

Key phrase- 'The ball was already rolling'. People talk about how hard it is to get help and then when they break through, things seem to take on a life of their own.

Feelings- Me angry again at the difficulty people have. Are they only angry in retrospect because they can now piece it all together and see the inadequacies? When people are more sure that it is mental illness do they get angrier beforehand?

Fed-up that this participant was 'fobbed off' and made to take her daughter home. Getting tired of hearing how inadequate the service is. It seems so obvious.

21.5.98

Seems that there are two types of response to : the 'uniformed' who don't realise until the last minute and then a crisis occurs; and the 'informed' who know where and how to get help but still don't get it until a crisis occurs. What's this about?

Theme- Guilt over how it got caused- divorce, especially with mothers of daughters. Is this the same as Blame?

Theme- Blame. Blaming self for somehow causing or encouraging the situation. Is this the same as Guilt?

Theme- keeping it within the family

It seems that majority of people try to keep it within the family. It's only if someone within the family has some understanding of mental illness that it is raised. Very few had anyone with any knowledge. Only Mrs X with her leaflet.

28.5.98

Hard to do this interview because I was late and the tape snapped, then batteries died. Now hard to listen to it, even remember it. Feeling that there are already favourite transcripts that I have and have spent more time thinking about them.

27.5.98

Soap operas. How they play a part in people's lives and how they educate people to mental illness among other things.

"I wouldn't have been surprised one little bit if the police had come up to say she was dead or.."- What a way to be left feeling for so long.

From Mrs -- I realise I am using a lot of her expressions and explanations to explain and reflect later interviewees experiences. E.g. that a lot of behaviour was not totally 'understandable'.

Theme- Beginning to find you are becoming unable to rationalise and explain the person's behaviour. Behaviour is often compared against the 'norm' of what you would expect someone else to do. This is often an internal, private comparison against your other children. Comparison with other people's children rarely happens, even if you know someone else with a schizophrenic son (e.g. Mrs -). Discussion only seems to take place with spouse to any great extent. How does this compare for someone like Mr -, who can't compare with anything else. Some people who had past experience could draw slightly on this knowledge (e.g. Mrs -), if not for diagnosis but for management.

I really like listening to this woman's tape. I feel that she has got a good understanding of the situation. She's not just moaning on.

22.6.98

I've now started to draw up little calendars so I can tick off the days. I keep coding and categorising my time with arrows and lists so that I can connect everything up. I'm watching the football and trying to type my results up at the same time. I can't believe that England are losing to Romania.

27.6.98

I had supervision and I've got to re-write my themes because they're too concrete. My brain feels like concrete.

2.7.98

I just had a brain-wave and managed to write my theoretical framework in a couple of hours. How on earth did that happen? I was just talking with my husband and moaning on and on about how my brain won't work and how I don't know what to write and how I can't make sense of anything, ever, moan, moan, moan....when he said "But you've already worked out the theory, wasn't it just those phase things you were showing me?". I can't believe how stuck I manage to get myself. And he was right (of course).

14.7.98

This is going to be my last entry. My brain is dead and I'm tired. I just can't wait to hand this in and go on holiday.

APPENDIX SEVEN

Respondent Validity Study: Summary Sheet

Dear

**Study: Exploring the experience of deciding to seek help for a relative
suffering an initial episode of schizophrenia**

Thank you for your participation in the above study. The fact that you gave up your time to share your experiences with me was very much appreciated.

You may remember from our discussion that I indicated I would feed the preliminary results back to you and that you agreed to comment on their accuracy.

I would very much appreciate it if you would take the time to read the enclosed results and let me have your comments. This is a very important part of the study as it helps to ensure that the interpretations of the interviews are as accurate as possible.

It would be very helpful if you reply as soon as possible (within a week) so that your comments can be included in the final write up.

I look forward to hearing from you soon. Thank you once again for all your help.

Yours sincerely

Wendy Pearse
Psychologist in Clinical Training

PRELIMINARY RESULTS

Explanation of the analysis

16 interviews were undertaken and for each interview a transcript was typed up. All the transcripts were then analysed both individually and in combination with one another. By doing this, common threads and experiences were identified. These common threads and experiences fell into three groups (known as 'themes'):

- 1) Effect of the help-seeking process on the family;
- 2) Particular issues that families had to consider when seeking help;
- 3) The stages of the help seeking process.

Within each 'theme' the common threads and experiences were divided up into a number of different categories.

As well as the themes and categories, there were also three major 'contextual' factors identified. These were considered to have a general influence over the entire process of help seeking.

Aim of the analysis

The eventual aim of the analysis is to combine all the themes, categories and contextual factors in a meaningful way and so produce an initial 'model' or 'theory' that explains the process by which people seek help for relatives with schizophrenia.

Once I have your comments I will be able to progress the analysis onto this next stage. All the participants will, of course, receive a summary of the research when the final report is completed.

Instructions

1. Please could you read through the results carefully, making any comments you wish, both positive and negative. You can write these on the sheet itself and on the blank sheets attached to the back.
2. As well as your general comments, I would like you to bear in mind the following issues as you make your comments:
 - i) Do the categories and themes make sense to you? Do they feel 'right' to you, or not?
 - ii) Do the categories and themes fit with your experience?
 - iii) Is there anything missing, or anything that needs to be emphasised more (or less)? Has anything been misinterpreted?
3. Please return your comments to me, in the stamped addressed envelope provided. It would be helpful if you could reply as soon as possible, preferably within a week.

Thank you

Preliminary Results

Theme One: Effect of the help seeking process on the family

1. Feelings

The whole process was marked by very strong emotions. These emotions were mostly negative and painful. Examples of feelings were: confusion, frustration, desperation. Families also expressed how much stress and strain they felt.

2. Experience of Professionals

The experiences that families had with mental health professionals seemed to have an impact on how families felt in general. Poor experiences tended to add to the family's stress and distress. These experiences included: general lack of explanation; lack of warmth and compassion; lack of insight into family's position; lack of support after discharge. Where positive experiences did occur this tended to help families to cope.

3. Knowledge

Mostly people felt neutral or open-minded about mental illness, although for many people, particularly in the early stages, schizophrenia was viewed as frightening and a 'hopeless' condition. Views about mental illness did not seem to influence whether people sought help or not.

Most people did not have any prior experience of people with mental illness. Where people did have experience it did not seem helpful in the help seeking process. However it was helpful in others ways such as: helping people to 'come to terms' with their experience; and practical ways in which to manage the patient. If people had experience of the health system from other sources (e.g. working for NHS) then this did help the help seeking process because they had more understanding of who to approach and what services they could expect.

Most people wanted information about what was happening to their relative and the majority of people read in order to inform themselves. Most people, however, at least in the initial stages, found that they received little information from the mental health professionals. Information seemed important as a way to feel more active, more empowered and less 'helpless'.

4. Isolation

There seemed to be two aspects connected with isolation. The first related to the whole experience being one which was out of the 'norm', something that was beyond usual experience. This meant that people often had no idea of what they were dealing with or the best way to manage the situation. This seemed to account for much of the confusion and isolation people felt. The other aspect related to the level of support and understanding received from other people (e.g. friends, family, professionals). In many cases people felt they were left to cope on their own.

5. Change

For better or worse people seemed to have had to deal with a lot of change. This revolved around three key areas. The first were personal changes (e.g. feeling weak or shattered, becoming more tolerant). The second area involved the way the family had changed. Examples of this included: adapting or changing living arrangements; 'splits' and divided loyalties between family members; different roles taken on within the family. This also included how the relationship with the patient had changed (e.g. levels of independence)

The third area was related to how the experience had changed people's lives in an overall way in order to accommodate the illness (e.g. work, social life, routines). This also involved the changed hopes and plans for the future, for both the relative and the patient.

Theme Two: Particular issues that families had to consider when seeking help

1. Family Decisions and Loyalty

Most people did not discuss their concerns about their relative with anyone outside of the immediate family, especially in the early stages. This seemed to be related to loyalty and respect for the patient's privacy. However, particularly in later stages, it may also have been related to the stigma of mental illness.

The decision to seek help was made, in the main, by one family member, often after consultation with other family members. The decision maker and the help seeker were most often the mother of the patient.

2. Independence versus Over-intrusiveness

This issue relates to how much responsibility and action the family should take in regard to the patient. A lot of families had to struggle with the tension between:

- a) trying to protect, and act in the best interests of, a vulnerable person and;
- b) being over-intrusive in a person's life.

This became more complicated if the patient was over 18 and unwilling to seek help.

The nature of schizophrenia seemed to have an impact here, particularly when patients were secretive, paranoid or withdrawn. Sometimes patients had tried to seek help during the initial stages of their illness and the family had been unaware of this.

Theme Three: The stages of the help seeking process

1. Search for an answer

This seems to be what 'drives' people to seek help and to keep on trying to get help even if it is difficult. It seems to be in the form of a 'nagging suspicion' which gets triggered by various factors such as changes in the patient's personality or behaviour.

2. Rationalisation

This is the process by which people try to make sense of what is happening with their relative. The underlying notion is related to events or behaviours being somehow 'explainable' or 'unexplainable'. When events or behaviours are still 'explainable' (e.g. teenage behaviour, stress) the drive to seek help is not very strong. When behaviours start to cross over and become 'unexplainable' (e.g. wild mood swings, very suspicious) then people are more likely to start to look for help.

3. Gathering evidence

'Evidence' is what families use to help them decide to seek help. Examples of evidence include: the patient is acting out of character; whether the patient's behaviour is excessive in any way or aggressive; whether the patient's behaviour is explainable in some way.

4. Help seeking

Initial contacts seem to be quite informal where concerns are 'checked out'. Initial contacts tend to involve people who are not mental health professionals (i.e. extended family, teachers, vicars, help-lines, Accident and Emergency staff).

If the family goes on to seek more help, then the GP is usually the next contact. The GP may or may not refer onto further mental health professionals (e.g. psychiatrist, psychologist). Continuing contact with the GP seemed to be important. A good relationship with the GP made it easier for relatives to get the help they needed.

It was also noticeable that in many cases the first contacts with psychiatric services were often unsatisfactory for the family. Often families would have to be very insistent and persistent to get the care they thought was appropriate.

5. Progression

This issue is related to how the help seeking process progresses through its stages although not every family goes through them all in order and may indeed skip earlier stages according to the strength of 'evidence'. The process may progress in an on-going way, steadily, as 'evidence' is gathered by the relative. It may also stop or start at any point. This is dependent on various factors (e.g. advice from others, behaviour of the patient).

One major influence on this process was a 'crisis' (e.g. aggressive behaviour, suicide attempts). This may be the starting point for help seeking for some families, or may speed up an already on-going process.

Contextual Factors

There seemed to be three particular factors which had a general influence over the whole process. These were:

1. Whether the patient lived at home or not;
2. The course of the illness (i.e. whether it was slow to build up or had a sudden onset);
3. How willing, or able, the patient was to be involved in the help seeking.

APPENDIX EIGHT

Feedback from Respondent Validity Study

Feedback from Respondent Validity Study

Fourteen summaries were sent out. Twelve were returned. The results are presented below:

Participant 3

"I have read through your preliminary results several times and can find nothing more to include. To my mind you have covered all aspects of our experiences a family living with a mental illness, and the outside attitudes to our family member and ourselves."

Participant 4

"Your summary was good. I agree with the points. Would like to make the point that side effects of medication should be made very clear to patients and carers."

Participant 5

"Seems all OK to me. Was only too glad to help."

Participant 7

"I think this report has covered most of the negative side of my experiences. I find it unbiased and fair. I've nothing to add on the positive side... ..I am pleased with everything you have put in the report. Please don't take anything out. It is such a shame that it is true. Information and co-operation are so important in every other part of the medical profession. Secrecy and unwillingness to communicate do not protect a mental patient. Staff can ignore if they wish 99.9% of what you say but they could listen. Thank you for listening and thank you for so obviously understanding."

This participant went on to suggest two further points:

- 1) The need for consultants to see patients as whole people not just a schizophrenic patient as they often have problems that are outside of mental health
- 2) The need for a private place to talk with staff away from the ward, especially if the person is paranoid.

Participant 8

"The categories and themes summarise most of our experiences well. Relations definitely need support and understanding from the professionals on a continuing basis, but more especially in the early stages when they are themselves confused."

Participant 9

“By and large we agree in principle with your comments. However, with regard to warmth and compassion they (professionals) could not have been better. As for support after discharge this alone was very good. Re: splits in the family, the opposite was true in ours. we seemed to close ranks and this gave my husband and I additional psychological strength.”

Participant 10

“I find this to be quite accurate.”

Participant 11

This participant agreed that all the categories were “very true” and in total it was a “A very good summing up of your investigations”. Specific feedback on categories is detailed below.

Experience of Professionals:

“My experience was of lack of support”

Knowledge:

“Most of my knowledge came after much reading but mainly through caring for my son all the time”

Isolation:

“In the early days of the illness it was a question of having to cope with the situations as and when they arose”

Participant 12

This participant made comments under several categories

Feelings:

“Helplessness”

Experience of Professionals:

“Agreed”

Knowledge:

“I was struck by the number of people and friends, who, on hearing of our son’s illness, told us of their own previous mental illnesses and recoveries. This gave some reassurance, as intended.”

Family decisions and Loyalty:

“We were open about it. Never considered it a stigma, more an affliction.”

Participant 13

“The professional people I went to seek help from have made me as ill as the patient and I have no confidence left.”

Participant 14

“Your paper seems to be a fair assessment of my own experiences. It is not until the patient is sectioned that any real help is obtained. Relatives, usually the mother, feel very isolated and vulnerable. If the patient will not accept help it is difficult to get any assistance and whilst I agree that a patient’s privacy must be safeguarded, I feel more support is needed to help families. Voluntary patients can discharge themselves with little or no back up. A helpline might be of assistance.”

Participant 15

“Our negative, fearful views on mental illness delayed for many months, our seeking help(e.g. media images of ‘looney bins’).”